



## PHD

**Are people with learning disabilities really being empowered?**

**An ethnography exploring experiences of empowerment policies in UK social care support.**

Banks, Carys

*Award date:*  
2018

*Awarding institution:*  
University of Bath

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**Are people with learning disabilities really being  
empowered?**

**An ethnography exploring experiences of empowerment  
policies in UK social care support.**

Carys Anna Banks

A thesis submitted for the degree of Doctor of Philosophy

University of Bath  
Department for Health

September 2017



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## **Abstract**

This thesis explores how government policy impacts everyday support settings in UK-based learning disability social care. The empirical research took the form of an ethnography conducted within two learning disability social care provider organisations based in the South West of England. I spent time with people with learning disabilities and staff members in a range of settings, including home and day services. I also spent time with independent community organisations, including an advocacy service and a café supporting people with volunteering opportunities.

Contemporary social care policy aims to reduce the exclusion and inequalities that people with learning disabilities experience by empowering them, as much as possible, with independence and equal access to community life. Within this, a range of social, political and economic philosophies have come to shape policy objectives, constructing different identities for people with learning disabilities. Yet, despite this, across the decades, services have continued to be plagued by cases uncovering fundamental failings, which at worse, have led to terrible abuses of people with learning disabilities. To unpick further the complexities of empowering people with learning disabilities, I used ethnography to understand the ways that policy objectives were experienced in everyday practice.

The key findings from my research challenges current empowerment approaches which aim to improve the lives of people with learning disabilities. The expectation is that aspirations of independence and community living are possible to achieve if the necessary resources are made available. However, for people with learning disabilities, their intellectual – and for some physical – impairments meant that they tended to experience difficulty in meaningfully assuming the rights and responsibilities that accompany these aspirations. Yet, the focus within policy that these are aspects of a ‘normal’ life is such that, in everyday settings, people were compelled to partake in a performance, which sustained the notion that these are realistic expectations. Ultimately, these factors undermined relationships between people with learning disabilities and the people supporting them, alienating them from each other.

## **Acknowledgements**

This piece of work obviously would not have been possible without the participation and cooperation from all the people involved in the research who let me spend time with them. As well as enabling me to conduct this ethnography, on a personal level, my experiences with many of them have profoundly changed me in ways that are not possible to describe here.

I am enormously grateful to my supervisors, Dr David Wainwright and Professor Rachael Gooberman-Hill. Your contributions, support and time have meant an immense amount to me, and I really do not think I could have asked for a better combination of people to have guided me through this process. It is because of you both that I have been able to produce the type of doctoral research that I had hoped to. I am also very grateful to my funders, the Economic Social Research Council, for funding this research.

It is in no way an exaggeration to say that my doctorate and the subsequent creation of this thesis would not have been possible without many of my friends and family who have, in their different ways, supported me over the last few years. I cannot thank them all in person here, but I must acknowledge the following individuals: my sister-in-law, Nicola, who is a paragon of excellence in proof-reading; my friend for life, Maxine, who has helped me through the hardest of times; Philippe, whose depth of kindness will ever astound me; and finally, my ever patient, generous and inspiring family, Sheila, Derek, Dylan and Morgan. If indeed this does prove to be a successful piece of work, in many ways the success has been down to you all. I am and will remain eternally grateful for everything you have done. Finally, I would like to dedicate this thesis to my magnificent niece, Amber, who is a shining light in our family.

***‘Aristotle’s axiom: The worst form of inequality is to try to make unequal things equal.’***

**— Laurence J. Peter, *Peter’s People and Their Marvelous Ideas***



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## Introduction

### Failings in learning disability support: why are we still here?

The last few years have seen several cases of exposed failings across a variety of UK learning disability services in public and private sectors, some of which have been widespread. The most recent of these to emerge on the social care landscape was the 2011 Winterbourne View scandal, in which the BBC current affairs programme, *Panorama*, exposed the terrible abuse and neglect taking place at an assessment and treatment unit in Bristol for people with learning disabilities (Department of Health, 2012; Bubb, 2014). The BBC had been contacted by whistle-blower Terry Bryan, a charge nurse at Winterbourne View, because his complaints to South Gloucestershire Council, as well as the private company, Castlebeck Ltd, who owned Winterbourne View, had been consistently ignored. Hindsight now reveals the extent of the lack of judgement in not responding to Bryan's reports, as the airing of the five-week undercover BBC investigation revealed staff committing abominable acts, such as:

‘slapping extremely vulnerable residents, soaking them in water, trapping them under chairs, taunting and swearing at them, pulling their hair and poking their eyes’ (Hill, 2012).

Two months following the screening of the *Panorama* investigation, a serious case review undertaken by the Care Quality Commission (CQC) found that there was a ‘systematic failure to protect people’, and that ‘some staff were too ready to use methods of restraint without considering alternatives’ (Rosenbach, 2011). Winterbourne View provoked huge public outcry, which led to 86 organisations writing to the then prime minister, David Cameron, calling for the closure of inpatient settings and for action to stop a repeat of these abuses. In response, the government pledged to move people out of inpatient accommodation and into the community (Bild, 2016). However, by 2014 this pledge had not been fulfilled, which prompted NHS England to request an independent review, led by

Sir Stephen Bubb, proposing, among other things, closures of inappropriate inpatient settings (Bubb, 2014). Following this, in 2014 the Transforming Care Delivery Board was established, which is currently working to develop a transformative model of health and social care services for adults with learning disabilities. This board is particularly focused on people who are at high risk of being admitted to inpatient units, including individuals with autism, mental health conditions and/or who display challenging behaviour (Association of Directors for Adult Social Services, Care Quality Commission, Department of Health *et al.*, 2015).

Shockingly, the abuse and neglect which took place within the Winterbourne View assessment and treatment unit was soon shown to be revealing of far more endemic failings in the care and treatment of individuals in inpatient settings. This case also shone light on how inpatient settings had been unnecessarily used across services in England for decades. Not only this, but that thousands of people had literally been living in these services for many years, even after their treatment had ended. Moreover, it was also revealed how, rather than moving people into community-based accommodation following the closure of the campuses and long-stay hospitals (large institutions which tended to be set outside of communities, that had previously been the primary means of care for people with learning disabilities), it had been common-place for some people to be moved directly into inpatient settings (Goldring, 2009). Unfortunately, because many of these individuals were not supported by family or advocates to speak on their behalf, they permanently remained in these settings when they could have been living in the community (Department of Health, 2012).

The scale of failures that the Winterbourne View scandal brought to light was, for contemporary health and care services, unprecedented. Unfortunately, however, it was not the first time that learning disability services had shown to be wanting. In 2006, after concerns were raised by East Cornwall Mencap about abuse taking place in the Cornwall Partnership NHS Trust, regulators in the UK and England, the Healthcare Commission (HCC) and the Commission for Social Care Inspection (CSCI) found 'many years of abusive practices at the trust including physical, emotional, environmental and financial abuse' of people with learning

disabilities (Joint Committee on Human Rights, 2008). Again in 2007, following several allegations, including of physical and sexual abuse, the HCC were asked to investigate services in Sutton and Merton Primary Care Trust, which found 'outmoded, institutionalised, care which had led to the neglect of people with learning disabilities'. Furthermore, it was found that people were being inappropriately and unnecessarily restrained (Joint Committee on Human Rights, 2008).

Perhaps one of the most shocking and brutal cases from that time was the murder in 2006 of Stephen Hoskin, a man with learning disabilities. After his mother, who was his main carer, became too unwell to support him, new accommodation was found for Stephen. At first this was in a sheltered service, which was travelling distance from his childhood home where he was looked after by his local community. However, it was latterly decided that Stephen should be enabled to become more independent, after which he was moved to a bedsit where he lived with less support. It was after moving into his own flat that Stephen was taken in by a gang of individuals who systematically abused and tortured him over a number of months. Eventually, on the night of the 5<sup>th</sup> July 2006, this culminated in his murder:

'Three of the gang, one a girl of 16, tortured him until he falsely confessed to being a paedophile. Their kangaroo court sentenced him to death, forced him to swallow 70 painkillers and frog-marched him to the top of the Trenance viaduct that soars over St Austell. High on drugs, alcohol and power, they rolled Mr Hoskin a last cigarette before forcing him over the safety rail. As he clung on by his fingertips, the girl, Sarah Bullock, stamped on his hands and he fell 30 metres' (Morris, 2007).

A serious case review (SCR) published in December 2007 found that Stephen had received regular visits from social workers and police, even when the individuals who would later kill him were living in his flat. However, because Stephen was viewed as a capable adult, his decision to terminate his support from Cornwall's council services had not been investigated. As a result, he then

lost all control to the people who abused and eventually killed him (Flynn, 2007). Following this, recommendations were made that any significant decisions taken by a vulnerable person regarding their support should be investigated and followed up with an assessment of their capacity. In addition, recommendations about improving communication and sharing information between separate agencies involved in care and support of vulnerable adults were given.

I feel it is important here to be clear about the kinds of abuses to which Stephen was subject and those which took place at Winterbourne View, and to distinguish them from mistakes and/or failings that have been revealed by other cases within learning disability practice. Certainly, both Stephen's killers and some of the individuals working at the Winterbourne View assessment and treatment unit committed terrible abuses. Arguably however, these events were the catastrophic outcome of a small group of people using an exposed vulnerable person or an enclosed setting as an outlet for serious violent tendencies. Tragically, the individuals who committed these terrible acts may themselves have also been victims of abuse at one time or another. This is an important point to make as it is crucial not to contribute further to the positioning of 'saints' and 'sinners' that so often characterises media reports and which, by asserting individual blame, can serve to mask fundamental problems within services.

Although extreme examples, I believe that both Winterbourne View and Stephen Hoskin's murder are illustrative of these fundamental problems within learning disability support. The events at Winterbourne View showed how, within segregated and institutionalised settings, certain behaviours by some individuals, which would not have been publically tolerated, were difficult to control and as a result all too easily became culturally assimilated into everyday practice. As was evidenced at Winterbourne View when violence towards vulnerable people with learning disabilities became understood as 'the Castlebeck Way' (Converse Prison News, 2017). Crucially, Winterbourne View uncovered the vast degree to which this kind of cultural assimilation was taking place in institutionalised settings, as services across England unnecessarily segregated and restricted people's freedom. By contrast, Stephen's murder indicated how enabling a

vulnerable person with too much freedom left them open to other forms of exploitation and abuse.

Both these cases show a fundamental inability by services to deliver support for people with learning disabilities in ways that meet policy commitments. Broadly speaking, from the 1950s, UK-based learning disability policy has been based on the perceived emancipatory potential of being in control of one's life and the importance of having access to an 'ordinary' way of life (Towell, 1988), such as having a home, getting a job and having relationships (Department of Health, 2001). It is these kinds of independence and social inclusion that are believed to give people the opportunity to live 'well' (Johnson, 2013). Crucially however, there is also a recognition that individuals with learning disabilities are considered to be 'vulnerable adults' and so in need of protection (Care Act, 2014).

It certainly cannot be doubted that governments, as well as other organisations/movements, have been – and still are – driven by a strong benevolent desire to support people with learning disabilities in ways that are free from mistakes, such as abuse and neglect, and to enable them to live fulfilling lives. Yet, despite all the benevolent aims and reforms, historical events show that services continue to be plagued by catastrophic failures. Surely, this begs the question: how has this been possible after what has now been nearly 70 years of policies that claim to have been empowering people with learning disabilities? Indeed, it is important not to underestimate the implications of such problems for these services as they not only indicate serious failings that need to be addressed, they are an indictment of the decades of policy rhetoric claiming to have empowered people with learning disabilities.

One way of determining why supporting people with learning disabilities can be so problematic relates to the simultaneous commitment within policy governing this support to both empower and protect adults with learning disabilities, which is highly complex and difficult to achieve. As a condition, learning disability is experienced in highly heterogeneous ways; some individuals can live relatively independently with minimal support, while others require support 24 hours a day to manage almost every aspect of their lives. For instance, although some



individuals may, from their physical appearance, appear to be capable, because their condition impacts their cognitive abilities, other vulnerabilities can often be masked. Due to the varying, and often not immediately apparent, ways that people require support, determining the lines between balancing empowerment and protection can be problematic.

Accordingly, when we think about these aspects of empowerment and protection in the lives of people with learning disabilities, what do we really mean? If we think of empowerment in terms of autonomy, can this be described as the capacity of a rational individual to make an informed, un-coerced decision? If so, to what degree should people with learning disabilities be free to make decisions for themselves? Conversely, at what point should they be stopped from doing something that they want to because it is considered to be unwise and/or unsafe? How far can these acts of intervention be taken before legitimate coercion to keep people safe becomes a violation of their liberty? These questions have both explicitly and implicitly come to shape policy and practice within contemporary learning disability social care support in the UK, as well as within services across other nations that define themselves as liberal and social democracies (Johnson, 2013). Certainly, the basis of these questions are themselves ones that have come to shape central components of Anglo-American and European social and philosophical thought for hundreds of years. The impetus here largely boils down to determining how the good life might be achieved for both individuals and society at large, the definition of which has come to encompass a variety of forms (Carel, 2017).

Intertwined within these definitions of living a good life as individuals in communities are wider concepts of structure-agency and the role that the state plays in people's lives. Again, within the Anglo-American and European canon there are contesting ideas about what state-citizen relations should actually look like, in terms of whether the state should be a lesser or greater presence in enabling people to flourish in their lives (Kymlicka, 2012). Crucially though, in terms of freedom and security, in order to satisfy one condition, the other must always be curtailed to an extent. In everyday life, this tension is continually negotiated as people are given various forms of freedom, but they also make

compromises by obeying laws and regulations. In this sense, these tensions and the real-life consequences of them are deeply rooted in societies that have been influenced by Anglo-American and European social, political and philosophical thought (Kymlicka, 2012). Although I refer here to these theories, they are highly complex and authoritative explanations of them go beyond the scope of this doctoral study. However, for the purposes of this thesis it has been necessary to point towards the philosophical roots of these ideas in order to show how they have influenced and shaped policy governing care and support provided to people with learning disabilities in the UK.

For adults with learning disabilities, it is arguable that there are added complexities to these tensions between freedom and protection. Importantly, in being considered as eligible to receive support from others, there is a recognition that the ability of people with learning disabilities to take care of themselves is, to varying degrees, limited by their condition and needs. All this raises questions as to whether, and if so how, the aspirations of freedom that are promoted through learning disability policy can be balanced with the need to protect people whose condition means they experience difficulty in managing independently.

It is these tensions that have been the focus of my doctoral research, and in this thesis I have sought to explore how macro political conceptions of what it means to live well are incorporated and understood within people's everyday experiences and relationships of care. In being positioned as various kinds of emancipated agents, the lives of people with learning disabilities can be seen to reflect wider social, political and philosophical conceptions of how the route to individual fulfilment and the good life can be achieved. In this sense, they can be seen to act as a magnifying glass, exposing the areas where these conceptions may begin to break down. As we enter increasingly uncertain times socially, politically and economically, the need to understand, and possibly even broaden what it means to be human is urgent. Through this research, I have aimed to contribute to the role of the social sciences in striving towards understanding these uncertainties and their implications for people with learning disabilities. I hope that this research can in some way contribute to the work of others who

have also revealed the contradictions of defining what it means to be human in particularly narrow terms.

## **Thesis outline**

### **Chapter one:**

#### **Locating the development of UK learning disability policy**

In chapter one I locate the social, political and economic contexts within which learning disability policy has developed over the last 70 years. My aim in doing this is to show how these wider influences have defined and shaped this policy over time. From the mid part of the 20<sup>th</sup> century, societal perceptions that vulnerable people were best placed in institutionalised settings came to be superseded by ideas and belief emerging out of the social democratic post-war consensus and disability movements. Both these movements championed collective responsibility and individual autonomy and were the forerunners to a new model of care, which came to be known as Care in the Community (Department of Health, 1989). Then, with the onset of the neo-liberal era of the late 1970s, collective responsibility was replaced by the principles of free market capitalism, and autonomy of the individual became defined by self-interested enterprise. The approach of the Third Way, just before the beginning of the millennium, then saw an attempt at creating greater societal egalitarianism by reviving social democratic politics with a view to synthesising this with neo-liberal economics.

These movements have converged within contemporary learning disability policy in the broad forms of independence and community inclusion. With a view to emancipating people with learning disabilities, as well as to creating more cost-efficient services, the provision of state-led support has, in large part, been redistributed into the private and third sectors in the form of user-led decision-making and personalised services. Ideas of which were writ large in New Labour's 2001 learning disability White Paper, *Valuing People: A New strategy for Learning Disability for the 21<sup>st</sup> Century* (Department of Health), a policy document that continues to dominate the delivery of learning disability policy and practice. In describing the changing perceptions towards how best to support people with learning disabilities, I begin to build up a picture of contemporary policy

objectives, as well as the implications of this for lived experience of people with learning disabilities.

## **Chapter two:**

### **Literature review**

Chapter two reviews the literature that has explored and critiqued the ways in which the different social, political and economic philosophies which have shaped contemporary social care policy have come to construct a range of identities for people with learning disabilities. There has been much research that has sought to critique these philosophies and corresponding identities. Much of this has explored whether empowering people with learning disabilities with particular kinds of independence and inclusion has improved people's lives. In doing so, this has also led to debate around the nature of the relationship between people with learning disabilities and the state, and whether it is the state or independent sectors that would most enable people to live fulfilling lives. I review previous research in this area, with a view to indicating the gaps in knowledge that my study would fill. Finally, I argue that understanding these issues requires a methodological approach robust enough to capture the nature of people's situated experiences.

## **Chapter three:**

### **Methodology and methods**

The third chapter focuses on the theory and design underpinning the empirical stage of the research. Here, I set out an argument which justifies my use of ethnography. I do this by first defining this methodology and showing how it 'sits' in relation to my theoretical positioning and research question. In doing so, I indicate how this is favourable over other approaches driven by alternative theories. I then describe the places and people who were involved in the ethnography, and how access and informed consent of participants were sought. From here, I move on to the study design itself, including descriptions of the methods used to collect findings, as well as how these findings were analysed. I show how, through detailed participant observation (recorded with extensive

field notes), semi-structured interviews and informal conversations, I was able to capture rich, holistic insights into people's social relations and practices. From these insights, I was able to describe and analyse the emerging, subjective and interrelated nature of people's social and material worlds, including the explicit and implicit complexities – patterns, discrepancies and ambiguities – that made up their worlds (O'Reilly, 2009; Bates, 1996). Throughout this chapter, where necessary, I also acknowledge the reflexive nature of ethnographic research, including the ways that this approach gave rise to a number of analytical and ethical issues that needed to be considered within the study.

#### **Chapter four:**

##### **Introduction to the empirical chapters**

This chapter serves as an introduction to the main field sites that were involved in the research. This included two learning disability provider organisations based in the South West of England, which I have called 'Cambrick' and 'Singertree Trust' (all real names and places were replaced with pseudonyms). In addition to these organisations, I also spent time with independent community groups, including an advocacy service, which I have called 'Hear Us', and a church community project, which I have called 'Station Park Café'. In order to provide some details on the material and social fabric of these settings, in this chapter I draw on my field notes that describe my experiences of visiting these places. I hope that setting the scene in these ways will assist the reader in understanding the particular context of this study.

#### **Chapters five and six:**

##### **Empirical chapters**

Chapters five and six present the ethnographic material which describe the ways that both people with learning disabilities and the people supporting them experienced government policies in everyday social care settings. Given that there were vast differences between the experiences and accounts of people with learning disabilities, their support workers and other staff, I opted to separate these across two chapters, with a view to presenting this diversity. Despite their

vast differences, however, the experiences of each remained tightly bound up in the minutia of their everyday relations with one another. As such, these deeply enmeshed lives overlap across both chapters and are triangulated with my own experiences and accounts in order to present the themes that emerged from the findings.

These findings reveal how both people with learning disabilities and their support workers and other staff held differing expectations of each other. Support workers and other staff tended to be led by government policy, which directed them to support people to become as independent as possible and an everyday part of community life. Whereas people with learning disabilities were more inclined to seek informal, and at times emotional, engagement from the people supporting them. However, the focus within policy that particular forms of independence and social inclusion were aspects of a 'normal' life was such that, in the context of daily practice, support staff, and at times people with learning disabilities, were compelled to partake in a performance whereby there was an attempt to enact policy expectations. As well as continuing the perception that these expectations could be achieved, support staff were also compelled to ignore the emotional connections that people with learning disabilities sought from them. These factors undermined relationships between people with learning disabilities and support staff, ultimately alienating them from each other.

## **Chapters seven and eight:**

### **Discussion and conclusion**

In the discussion chapter I draw together all the themes that were presented and discussed in the empirical chapters four, five and six. I use these themes to develop larger overarching themes, with which I interweave existing literature and theory in order to set the findings from this thesis within a wider context of intellectual and theoretical debate. Here, I explore further the ways that policy compelled people to partake in a performance in order that aspirations relating to particular kinds of independence and inclusion could be seen to be taking place. I then position this alongside the empirical evidence indicating the unavoidable reality that in many ways people with learning disabilities remain excluded from

society. I then explore the concept of emotional labour in terms of how it is inherently present in types of work, such as care, and discuss the implications of this for both people living and working in support settings. Finally, towards the end of the discussion and into the conclusion, I locate contemporary learning disability policy objectives within political and philosophical conceptions of what it means to live a good life. In doing so, I explore the problematics of these conceptions when thinking about the lives of people with learning disabilities, and the implications this has for our understandings of what it means to be human.



## **What does it mean to have a learning disability?**

Before beginning, at this stage it will be useful to present a brief overview of learning disability, in terms of how this condition is both medically defined as well as what it means for people in an everyday sense. Within much Anglo-phone research, intellectual disability is now recognised as the formal definition for this condition (Schalock, Luckasson & Shogren, 2007). However, in this thesis I have mostly chosen to use the term learning disability. Learning disability was introduced into the NHS during the 1990s to replace the term mental handicap, which had become viewed as derogatory. Learning disability is used in UK government documents and widely across the UK (Walmsley, 2001), for example it is the term most used by the charity, Mencap, the foremost UK learning disability charity. In recent years, a number of self-advocacy groups have expressed a preference for the term learning difficulty (Walmsley, 2001). However, this can be confused with the use of learning difficulty in education legislation, which describes people who experience conditions, such as dyslexia, that affect only one aspect of a person's functioning – their ability to process information. By contrast, learning disability affects a person's overall intelligence and experiences across all areas of their life (Department of Health, 2001).

The Department of Health defines learning disability as a:

‘significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood’ (2001: p.14, para.1.5).

There are multiple causes of learning disability, but in all the learning disability occurs because the brain has been affected during its development. For instance, there may be complications before or during birth, or during childhood up to the age of 18. It is not always possible to determine what has caused the brain's function to be affected, and for some people with mild disabilities, the impairment may not be identified until adulthood, if at all. For others, whose impairments are

more marked, identification and diagnosis usually happen in childhood, for example, by a teacher at school or through developmental checks with the GP. After which, the child and their family will be referred to the relevant support services (Mencap, 2017a).

The definition of learning disability provided above covers a broad spectrum of the condition, which reflects the heterogeneous and complex ways that it can impact people's lives. Given this complexity, identification of the presence of a learning disability must involve a number of assessments – a low intelligence quotient (IQ) of below 70 is involved in this, but cannot be taken alone as confirmation of a person having a learning disability. In addition to an IQ test, assessments of adaptive functioning, including daily living and social and communication skills also need to be carried out (Department of Health, 2001). If diagnosis is being made in childhood, these are assessed by a clinician through structured interviews, and the results then compared with other children of a similar age (Mencap, 2017b).

There are a set of categories: mild, moderate and severely intellectually disabled which, albeit crude, can be followed to determine the level of a person's disability (Emerson & Hatton, 2008). Individuals considered to be mildly intellectually disabled may be able to live relatively independently with minimal support. As a result, their disability may not appear as immediately obvious, but they may require support with anything from reading forms to seeking employment. Importantly though, as I mentioned earlier on pp.11-12 although some individuals may, from their physical appearance appear to be capable, because their condition impacts their cognitive abilities, other vulnerabilities can often be masked. Others who are more severely intellectually disabled may still be able to do things for themselves, such as personal care, as well as express choices, including around what they like to do with their days. However, they tend to require continual support in managing many aspects of their lives. Further still, people who experience multiple and profound intellectual disabilities can be unable to physically do anything for themselves, meaning that they require support with every aspect of their lives 24 hours a day. Many people, irrespective

of their level of disability, may also experience physical and/or sensory impairments.

Some individuals also have a specific condition associated with their learning disability, which may mean that they require particular types of support and/or treatment associated with these conditions. For example, the genetic conditions, Down syndrome and Prader-Willi syndrome are associated with specific health problems (Roizen & Patterson, 2003; Butler, Whittington, Holland *et al.*, 2002). Elsewhere, some people who have learning disabilities also have autism, and there are various types of treatment and therapies available for the needs presented as part of these conditions (The National Autistic Society, 2017).

When transitioning into adult learning disability services, individuals seeking support are required to apply for a needs assessment through their local authority. In order to determine whether the person is eligible for support, as set out in the Care Act 2014, this entails a face-to-face assessment of the day-to-day support the person requires. Eligibility is determined on the basis that the individual is unable to independently manage with two or more of the following aspects: nutrition, personal hygiene, toilet needs, be appropriately clothed, be able to safely make use of their home, maintain a habitable home environment, develop and maintain family or other personal relationships, access and engage in work, training, education or volunteering, make use of necessary facilities in their local community, including public transport and recreational facilities, carry out any caring responsibilities they have for a child and, because of the above there is, or is likely to be, a significant impact on their wellbeing (Mencap, 2017c).

Following these descriptions of the ways in which learning disability is understood in medical terms as well as the everyday implications of this, I now move on to providing a description of the development of learning disability policy in the UK over the 20<sup>th</sup> century and into the 21<sup>st</sup> century.

## **Chapter one**

### **Locating the development of UK learning disability policy**

#### **Introduction**

In this chapter I locate the development of UK learning disability policy from the middle part of the 20<sup>th</sup> century and into the 21<sup>st</sup> century. In particular, I show the ways in which policy objectives have been shaped by a range of social, political and economic philosophies, which have intended to improve the lives of people with learning disabilities by enabling them with, often conflicting, forms of autonomy over their lives. These philosophies have also influenced the nature of people's relationship with the state in the context of social care support. In charting this policy development, I show how this has come to define and shape the contemporary social care support that we see today.

#### **Social democracy and the post-war Keynesian welfare state consensus**

Over the last seven decades, there has been a considerable shift in the central impetus of learning disability policy in the UK. From the mid part of the 20<sup>th</sup> century, the widely-held belief within UK policy-making has been that policy improves people's lives by empowering them, as much as possible, to become self-sufficient individuals who contribute to their communities. In this, there has been a move away from what are now described as overly paternalistic caring practices and towards supporting people in ways that promote their independence and life in the community (Department of Health, 2001; 2009a).

Importantly, these kinds of empowerment objectives have not always existed as the foundations upon which UK social care is based. For the first part of the 20<sup>th</sup> century, under the Mental Deficiency Act 1913, institutional care was the model provided by the state. By the 1950s, however, governments' views that institutional care was an appropriate model of support had begun to wane (Johnson and Walmsley, 2010). The institutional model has now come to be

viewed by governments as an archaic and inhumane relic of the Victorian and Edwardian eras (Department of Health, 2015). Such changing perceptions of institutional care are mainly due to its approach towards segregating disabled and ill people from the rest of society, which is now acknowledged to have encouraged poor caring practices, and to have led to the dehumanisation of people. There is indeed a substantial history of learning disability support prior to the first half of the 20<sup>th</sup> century, which has been explored and charted by a number of scholars (see for example: Thomson, 1998; Toms, 2013; 2017). To do justice to this extensive history would be beyond the scope of this thesis. Yet, in order to provide context, it will be necessary in the following paragraphs to make reference to a period that was pivotal for the direction of learning disability support in the UK: the post-war period.

The shift in views from the mid part of the 20<sup>th</sup> century regarding how to care for people with learning disabilities was significantly impacted by the creation of the post-war welfare state (Toms, 2017), when social democracy, which was directed toward the 'path of socialism' (Giddens, 1998), was beginning to shape British society. Broadly defined as the post-war Keynesian welfare state consensus or the post-war settlement between capital and labour, here the state took on a key role in attempting to reconcile the economic benefits of laissez-faire capitalism with socially collectivist and democratic values (Addison, 1975; Mishra, 1999). In the UK, the labour government of 1945 fundamentally transformed the country by nationalising major parts of the economy, with a view to creating a fairer society where necessary support would be provided 'from cradle to grave', and in which all people would have access to what they needed to live a better life (Burton & Kagan, 2006).

With the establishment of the welfare state, there was a recognition of the importance of social equality, and that those who were worse off than others, either by birth or situation in life, should be supported by those who were better off. Post-war social democracy in the UK saw a mixed economy of capitalist private enterprise combined with socialist economics that reinforced the collectivist and democratic values of the time – a sense of the importance of responsibility towards not only oneself, but also to others (Marshall, 1950 cited in

Hindess, 1987). The feeling of hope that these transformations brought about, and importantly, the role of the state in making them happen, is well encapsulated in the following lines by Joan Bakewell in her memoir:

‘Even as the fighting went on, the coalition government of World War II was already shaping departments of state to create a fairer and more benign society. It built on widespread hope of better things. Hope was the prevailing mood. Everyone hoped things would get better; and so they did. The 1944 Education Act would promote equal opportunity based on ability. I was to benefit directly. The Beveridge report of 1942 set out to tackle the five giant evils: squalor, ignorance, want, idleness and disease. It would update the National Insurance system and introduce the National Health Service; free medical treatment for everyone. There was sudden and delighted enthusiasm at being able to go to the doctors for free. It was obvious that these policies had huge immediate popularity. They seemed to the war-weary and run-down people of the country to offer some sort of on-going reward for the sacrifices they had made. The vision embedded in these five years was to resonate down the decades. The Labour party of the day sweeping into government in 1945, then losing to the Tories in 1951, had created deep-rooted change that shifted the kind of country we were: attitudes to wealth, taxation, health, education, the role of the state as acting in the interests of us all, shifted forever’ (Bakewell, 2016).

Along with this vision of society came the need to ensure the protection of individual rights. The Convention for the Protection of Human Rights and Fundamental Freedoms 1950 (now the European Convention on Human Rights 2002), which later became enshrined in UK domestic law in the Human Rights Act 1998, outlined the fundamental aspects of civil liberties that make up democratic societies (Council of Europe, 1950; Human Rights Act, 1998).

An example of how the post-war ‘prevailing mood’ of hope and the importance of equality and human rights affected societal views of disability were reflected in

changing attitudes towards the Eugenics movement, which by the 1950s was becoming increasingly discredited. Indeed, the Camphill Village Trust movement, a charity which provided – and still provides – support and work opportunities for adults with learning disabilities, can be seen as a reflection of these changing attitudes. Established in the 1940s by escapees from the Nazis, the Camphill movement set up small farming communities, first for children with learning disabilities, and later in 1955, at Botton Village in North Yorkshire, for adults. The main ethos governing the approach of these communities was that people with learning disabilities and those supporting them would live and work alongside one another, living off the land. In doing so, the charity wanted to emphasise the value of all human life and inspire a vision of social solidarity by showing that people with learning disabilities could live meaningful lives in the same way as non-disabled people (Camphill Village Trust, 2017a).

### **Influence of families and activist groups in closing the long-stay hospitals**

During the 1950s and 1960s, acting on the wider waves of social change brought about by the post-war consensus, it was in fact family members who were significant in instigating changes in the ways that people with learning disabilities were supported by the state. In particular, parent groups began forming in order to shed light on the ills of institutional care (Johnson & Walmsley, 2010).

The UK National Council for Civil Liberties (NCCL) (now known as Liberty), also campaigned alongside parent groups. Within these campaigns, there was a clear intent to express their message in terms that accorded with the strong sense of social democracy of the day. This is apparent in the pamphlet, published by NCCL in 1951, *'50,000 outside the law'* (NCCL, 1951), which Liberty now describe as 'a groundbreaking report on those unjustly incarcerated under the 1913 Mental Deficiency Act' (Liberty, 2017). The pamphlet articulated institutional care as an assault on the freedom and opportunities of those people consigned to reside in them. It also connected this concern with society at large, and the importance of acknowledging responsibility to its most vulnerable members:

‘The extent to which we guard their right to the fullest and most useful life, the extent to which we guarantee them the freedom which they can enjoy ... is a measure of the extent to which we ourselves are civilised’ (NCCL, 1951, from Stainton, 1994: p.132).

Campaigns, led predominately by families, as well as other activist groups, such as NCCL, were also emboldened by public scandals which began to expose the poor quality of support and living conditions of people resident in long-stay hospitals (Ferguson, 2007). These scandals also exposed the material flaws of this model of care that were contributory to its demise: it was highly financially inefficient, and it was not possible for the government to maintain these environments to the standard that was necessary to provide people with good care (Johnson & Walmsley, 2010).

The most notable case of a failing service to emerge during this time was the 1969 Ely Hospital scandal, which was exposed when, on 20<sup>th</sup> August 1967, the *News of the World* newspaper published allegations about the poor treatment, conditions and abuse of people with learning disabilities within the hospital. This then led to the subsequent Ely Inquiry, which, in exposing the ways that segregated care encouraged malpractice, rigorously set the ball rolling for transformative action within the NHS regarding its care and treatment of people with learning disabilities (Department of Health and Social Security, 1969). The inquiry was particularly politically influential, and following its publication, a review was established to assess the levels of care being provided across long-stay hospitals in the UK. This led to the beginning of the wide-scale closure of these hospitals, closures which would continue into the 2000s (Whitchurch Hospital, 2012).

### **Care in the Community**

Following in the wake of the Ely scandal, in 1971 the Labour government produced the White Paper, *Better Services for the Mentally Handicapped* (Department of Health), which acknowledged the need to transfer support for individuals from institutions and into the community. This brought into full force



the official policy of 'Community Care', that had first been established by the 1959 Mental Health Act (which abolished the 1913 Mental Deficiency Act), and had been followed by Enoch Powell's 1961 Minister of Health's *Ten-Year Plan* to close mental hospital services in England and Wales within 15 years (Ministry of Health, 1962). This marked the beginning of a long path in the transformation of social care policy-making in the UK. In focusing on community-based care provided by local authorities, this new model of care explicitly recognised that, as a large-scale health institution, the NHS was not best placed to provide people with the entirety of their support (Burton & Kagan, 2006).

By 1989, the White Paper, *Caring People: Community Care in the Next Decade and Beyond* (Department of Health), aimed to set the standard for community-based social services, designing them 'to provide the right amount of care and support to help people to achieve maximum possible independence and ... help them achieve their full potential'. With this, there was a drive to 'give people a greater individual say in how they live their lives and the services they need to help them do so' (Department of Health, 1989: p.4). In the UK, the Care in the Community initiative (Audit Commission for Local Authorities in England and Wales, 1986), as it was now termed, would remain the foundation upon which models of support were based for people with learning disabilities into the 21<sup>st</sup> century. As Kelley Johnson and Jan Walmsley point out:

'From being a problem that required institutional solutions, intellectual disability was, in the quarter-century following the Second World War, framed as a problem affecting whole families, which required the community to change and adapt to welcome them and their children' (Johnson & Walmsley, 2010: pp.88-89).

The move towards framing support within a community context also contributed to learning disability being perceived, not as something that could be located solely within the person themselves, but instead as something that was experienced by whole communities. The new model of Care in the Community was also 'calling into question the medical model' (p.89), and as a counter to

institutionalisation, this was setting the wheels in motion for thinking about people with disabilities living the same kinds of lives as their non-disabled counterparts.

### **Normalisation, social role valorisation and the social model of disability**

Bolstered by wider grass-roots activism characterised by The New Left (Lin, 1993), the decade of the 1970s brought with it a burgeoning in movements and theories that sought to improve the social positioning of people with disabilities (UPIAS & The Disability Alliance, 1976). Out of this time also emerged highly influential theoretical ideas that would have lasting impact on both societal perceptions and policy directives for people with learning disabilities.

During the 1960s, the approach of normalisation – the belief that people with learning disabilities should be entitled to an ‘ordinary life’ – was used to challenge institutionalised services and to promote the importance of community living (Nirje, 1969). These ideas were later popularised by the German-American academic and professor of special education, Wolf Wolfensberger, who adapted normalisation into social role valorisation (SRV), and expanded the definition to apply to all services that supported the needs of disadvantaged and undervalued groups in society (Wolfensberger, 1970; Wolfensberger & Tullman, 1982).

Although the principles underpinning normalisation and SRV were of significant import in contributing to the closure of large-scale institutions and segregated living, the ways these principles have been incorporated into services has, at times, been problematic. These principles gave credence to living a particular kind of ‘normal life’, which some activist groups have latterly argued constrains people from flourishing on their own terms (Johnson & Walmsley, 2010). From the mid 1970s, however, a social movement and subsequent theory developed that would transform the discourse of disability. In 1976, in their document, the *Fundamental Principles of Disability*, the activist groups, the Union of Physically Impaired Against Segregation (UPIAS) and the Disability Alliance produced a definition of disability arguing that it is not people’s impairments that disable them, rather it is the set-up of institutions and social relations that do so:

‘Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called ‘disability,’ of people with such impairment. Thus, we define impairment as lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. Physical disability is therefore a particular form of social oppression’ (Union of Physically Impaired Against Segregation & The Disability Alliance, 1976: p.14).

Following this, the British disability theorist, Mike Oliver, coined the term, the social model of disability to provide a theoretical counter to what he and others saw as the ways that disability was overwhelmingly defined in terms of a person’s individual biomedical pathology. The argument was that this positioning of disability as an individual problem or tragedy causes disabled people to be viewed as different, even inferior, and this fails to recognise that disability is a form of structural oppression (Oliver, 1983). The social model has been used by many activists to highlight the various material and social barriers that people with impairments experience in public life, such as inaccessibility in public spaces, transport services, education and working environments.

Since its formulation, however, the social model has come under much scrutiny, with critics arguing that it fails to take account of the subjective experience of material impairments, as well as the individual differences of people’s life trajectories (Bayley, 1991). However, Oliver has responded to these criticisms, accepting that the social model cannot act as an all-encompassing theory to explain the lives of people with disabilities in their totality. He argues instead that it is a vital political ‘tool’ to argue for and defend the rights of disabled people

against oppressing definitions of impairment and difference (Oliver, 2013: p.1025).

More recently, this theory has been used to deliberate further on the conceptual forms of social barriers that are experienced by people with learning disabilities, such as social stigma and exclusion (Oliver, 1990; 1991; 1996; Chappell, Goodley & Lawthom, 2001). Notably, the social model of disability has had a significant impact on bringing forth the case for citizenship for people with learning disabilities. In this vein, human rights in an individual sense have underpinned the direction of this approach (United Nations, 2006; Joint Committee on Human Rights, 2008). Indeed, the influence of an individualised human rights approach can be seen with the establishment of the Equality Act 2010 (formally the Disability Discrimination Act 1995; 2005) which marked the transference of disability rights from the Disability Rights Commission (DRC) to the Equality and Human Rights Commission (EHRC). In doing so, this sought to frame violations of this Act as violations of human rights. Under this, refusal or negligence on the part of employers, public services and institutions to ensure 'reasonable adjustments' for disabled people could be framed as a violation of their human rights.

The social model of disability, as well as theories of normalisation and SRV, came into existence following increased awareness of the negative effects of segregating disabled people from society, which creates barriers and a lack of opportunities (Tizard, 1964). This awareness about how people with disabilities should be treated can, in part, be traced back to the post-war consensus of collective responsibility, redistribution and the role of the state in making this happen. However, importantly, these movements can also be viewed as a move away from this consensus in that there is a strong focus on living and flourishing in individualistic ways, rather than through collectivist state support (Morris, 2011).

### **Neo-liberal economics and introducing a quasi-market into social care**

The movements amongst disability activists were taking place around the time when drastic changes were also happening within the UK's political system, which would significantly alter the role of the state in relation to its citizens. These radical changes, which came into full force under the New Right Thatcher (and Reagan in the U.S.) era, have now come to be characterised as neo-liberalism (Jessop, 2003).

Neo-liberalism is philosophically rooted in the political struggles of classical liberalism. However, whereas the classical liberals of the 1800s realised their freedom through political agency, neo-liberals tend to focus on economic agency. Though itself a broad term, comprising multiple interpretations (Willis, Smith & Stenning, 2008), neo-liberalism can be broadly defined as an approach to governing in which social, political and economic systems are constructed around the free market, so as to unshackle the individual from the constraints of state control, enabling them to freely exercise their individual autonomy (Peck & Tickell, 2002; Harvey, 2005; Willis, Smith & Stenning, 2008).

During the late 1970s to the early 1980s, the work of political theorist Edmund Burke, as well as American conservatism more generally, popularised views within the Thatcherism era of UK fiscal policy-making that 'big government' is a hindrance to individual freedom (Giddens, 1998). In addition to this, Thatcher drew on classical liberal economic theorists, Frederick von Hayek and Milton Friedman. In particular, Hayek's writings on the risks that a central authority poses to social life and individual freedom (1944), and in the importance of laissez-faire policies (1945), which were later used by Friedman to advocate for a redistribution of state held economic control (1962).

In a period of economic instability during the 1970s, in which there was a growth in globalisation and technological innovation, neo-liberalism emerged out of a growing rejection of the post-war Keynesian welfare state consensus, which appeared unable to contend with this changing world (Giddens, 1998; Kesselman, Krieger & Joseph, 2012). Seen through a neo-liberal lens, the consensus was now viewed as indicative of overly paternalistic state provision

controlled by those in power who believed they knew what was best for people, but who were actually constraining to enterprise. Furthermore, this style of a planned economy was viewed as an inefficient drain on government resources (Heppell, 2014). Returning to Joan Bakewell, her following descriptions provide further insight into the radical shift in societal views at the time:

‘The global oil crisis of the 1970s threw all this into turmoil. Faced with sudden change, people got fearful they would lose the good life they had come to enjoy. Hope and civic concern ceased to be the prevailing mood. Unions got greedy for their members, very greedy. Industries were convulsed by strikes. Working in Granada Television, I was part of a hugely successful public service series driven off air by escalating union demands. The impact spread; rubbish in the streets, bodies unburied, it became a battle of wills. In the end the Tories under Mrs Thatcher won. The consensus was over. So, the era of neo-liberal economics dawned. The prevailing ethic ever since has been individual freedom and competitive self-interest. Business and employment were about rivalry and money. It began the great divergence in wealth between rich and poor which blights the world today’ (Bakewell, 2016).

Through these radically shifting ideas, government’s role in both social and economic policy were being reshaped, and individual freedom and the free market became entwined together in the form of radical individualism (Leys, 2001). Although Hayek was one of the most influential figures in the creation of neo-liberalism, in fact his original vision, that it is through altruism that the public servant will be incentivised to meet the needs of their clients, was to be supplanted by a market based system in which self-interest would be used to spur the provider into meeting the needs of their customer, *i.e.* they meet the customer’s needs in order to keep their business afloat and make a profit. In this, social solidarity was now defined as ‘a self-generating mechanism’ of individual initiative, which could best flourish within the market and without the interference of the state (Giddens, 1998).

In many ways, the disability theories proposing inclusion and social rights sat in ideological conflict with neo-liberalism – in terms of the clash between equality and free market principles (Marshall, 1950, cited in Hindess, 1987). Yet, in some form the approaches taken by disability movements and neo-liberal economists appeared to express similar concerns, relating to the perceived threat of the state in constraining the rights and abilities of the individual to flourish. Normalisation, SRV and the social model of disability expressed this through advocating for the closure of institutions, and for enabling disabled people access to societal resources and citizenship, whilst neo-liberalism advocated for a redistribution of state services so as to unshackle the individual from overbearing controls. Importantly, these imperatives cut through one another in an economic sense too. The call by social rights and inclusion activists to close institutions slotted in nicely with the neo-liberal stance that state services were inefficient and too costly, which justified the need to redistribute service provision away from central government (Johnson & Walmsley, 2010).

### **Transferring powers from the state to people themselves**

Although there had been attempts by the state to provide community-based solutions after the closure of the institutions, these too became dogged by problems with costs, not to mention further scandals (Johnson & Walmsley, 2010). Following this, there became a need to fill the gaps in provision left by the failures of state care, and it was neo-liberal economics, in the form of a quasi-market style approach, that was perceived to be best placed to do this. However, the introduction of neo-liberal economic principles into the social care system was not simply a convenient solution to a failing service. Rather, the failures of state support emboldened those in the New Right who were set on fundamentally altering state-citizen relations (Johnson & Walmsley, 2010).

Redistributing responsibility and control of social care away from central government and into a quasi-market offered the opportunity to achieve what were fundamental aims of the new conservative government: to emancipate the social, political and economic rights of people in receipt of social care, while at the same time reducing costs (Strathern, 2000). With this, the ideal model became a mixed

economy of care provided by the state, voluntary organisations, private sector and family (Boxall, Dowson & Beresford, 2009). The 'traditional' family in particular was seen as a central factor in cementing this new relationship, as it was viewed as the 'functional necessity for social order' and crucial in the avoidance of societal demise (Giddens, 1998).

Within this notion of individual flourishing through the free market, the concept of inequality as a moral wrong was also being altered. The idea that government should play a role in enabling people to be free became framed as a stance of post-war political ideas which were akin to the exercise of authoritarian state power. With this, the belief that inequality should be done away with by the force of the government was also perceived to be similarly intrusive. Rather, advocates for neo-liberalism viewed equality of opportunity through the mechanisms of the market as the means by which individuals could reach their full potential. Crucially, by ensuring that individuals were free to flourish in these ways, this stance acknowledged the reality of economic inequality, but viewed it as an outcome of the natural order of things (Giddens, 1998).

### **The revival of social democracy and the Third Way**

Faced by the dominance of Thatcherism, during the 1980s the Labour government also began to focus upon the principles of individual freedom and choice (Giddens, 1998). Under the New Labour government, which took office in 1997, these ideas were incorporated into their policies under the banner of a new form of social democracy. This UK-based 'social democratic renewal' intended to differ from its classical predecessor by departing from the post-war consensus and developing a 'policy framework that would respond to change in the global order' of technological development and globalisation (Giddens, 1998).

Although the New Labour government shared the Thatcherism view-point that the market is more suitably placed than the state to deliver efficient and effective services, they defined their social democratic politics as representative of a vision of a greater egalitarian society. Prior to his election as prime minister in 1994, Tony Blair had described this variant on social democracy as 'ethical socialism'



(Blair, 1994: p.2), which was founded on the core social democratic principles of 'social justice, the equal worth of each citizen, equality of opportunity, community' (p.4).

Although it also defined itself as a departure from post-war social democratic politics, the Third Way was aligned with its predecessor in the sense that it aimed to reconcile social policies of the left with economic policies of the right (Giddens, 1998). For some, however, the Third Way represented merely an extension of neo-liberalism, most notably because it advocated freedom through marketisation (Romano, 2006). However, its supporters have argued that, rather than viewing market participation in terms of emancipating individuals to act as separate economic entities, Third Way politics intended to incorporate the idea that through community membership people should become responsible self-regulating citizens (Rose, 2000). In this, a distinct ethical dimension was incorporated into the political notion of what it means to be a citizen, as described by Tony Blair in The *Guardian* newspaper in 2004:

'In reality, I believe people do want choice, in public services as in other services. But anyway, choice isn't an end in itself. It is one important mechanism to ensure that citizens can indeed secure good schools and health services in their communities. Choice puts the levers in the hands of parents and patients so that they as citizens and consumers can be a driving force for improvement in their public services.

We are proposing to put an entirely different dynamic in place to drive our public services; one where the service will be driven not by the government or by the manager but by the user, the patient, the parent, the pupil and the law abiding citizen' (cited in Clarke, 2006: p.423).

In addition to drawing on a notion of the individual citizen as a responsible adult (Rose, 2003) who is expected to partake in ensuring the stability of the community in which they live (Beresford, 2002), the Third Way also incorporated the responsibility of the government, who play an important role in providing and

regulating the good life for citizens (Rose, 2000). With this, neo-liberal policies had said to have been worked on by incorporating elements of social justice, community ownership and government regulation into a free market system. With this they also framed inequality as something experienced by marginalised and vulnerable people who public services should be ensuring are given the same chances as other groups (Clarke, 2006). Accordingly, the Third Way aimed to reformulate relations between the state, public services and the general public (Pollock, 2005). Underpinning this revived social democratic politics was arguably an uneasy mix of equality of outcome with equality of opportunity (Giddens, 1998).

### **Valuing People and Valuing People Now**

As part of their focus on both equality and opportunity, in 2001 New Labour set out a vision for people with learning disabilities with the White Paper, *Valuing People: A New strategy for Learning Disability for the 21<sup>st</sup> Century* (Department of Health, 2001). This was the first learning disability white paper in 30 years (its predecessor had been *Better Services for the Mentally Handicapped* in 1971). Importantly, with this white paper the Labour government were acknowledging that, despite attempts to improve the lives of people with learning disabilities, many remained excluded members of society (Department of Health, 2001). This paper set out the agenda for support, in which Care in the Community was reinvented as 'social inclusion' for all. Central to this agenda were the principles of independence, rights, choice and inclusion as *Valuing People* set objectives for services to promote people's social and economic independence as well as equal access into community life. As the following lines from the opening section of the document illustrate:

'People with learning disabilities are amongst the most vulnerable and socially excluded in our society. Very few have jobs, live in their own homes or have choice over who cares for them. This needs to change: people with learning disabilities must no longer be marginalised or excluded. *Valuing People* sets out how the Government will provide new opportunities for children and adults with learning disabilities and

their families to live full and independent lives as part of their local communities.’ (Department of Health, 2001: p.2).

Almost ten years later, *Valuing People* was given new zeal with its follow-up paper, *Valuing People Now: A New Three-Year Strategy for Learning Disabilities* (Department of Health, 2009a). Whilst *Valuing People* introduced a defined set of core values that aimed to shape support in accordance with social and economic independence and inclusion in community life, *Valuing People Now* further reinforced employment as a means by which these core values could be achieved. In recognition of the fact that many people with learning disabilities do not have workplace skills, there has been a move towards setting up supported employment services and providing college courses, with a view to enabling individuals to develop these skills in safe environments, and to prepare them for the workplace. An example of this is Mencap’s ‘Employ Me’ service, which provides several services to encourage people into employment, such as pre-employment support, job coaching and in-work support (Mencap, 2017d).

It is perhaps both interesting and helpful to consider the introduction of employment here, as it could be viewed as representing attempts at a political repositioning of the social status of people with learning disabilities. In 1913, institutional care was perceived as the most appropriate way to look after people who were unable to look after themselves, which, in part, was defined by their inability to join the workforce. Now, in the 21<sup>st</sup> century, employment was being presented within policy as a means to enable people with learning disabilities to stake their social and economic claims in society.

### **Person-centred care/approach**

The individualised approach that the free market underpinned bore similarities to pre-existing ideas of person-centredness that had been developing within Euro-American health and social care services since the 1960s (Department of Health, 2007a; Department of Health, 2010; The Health Foundation, 2016). From the early 2000s, person-centred care was introduced as an official government model that would put control of purchasing services into the hands of people themselves

and their families. Through their purchasing powers, recipients of services were then defined as consumers/clients with choice and control over their lives (Campbell, 2001; Mansell & Beadle-Brown, 2004; Boxhall, Dowson & Beresford, 2009; Department of Health, 2009a; Department of Health, 2010). These aspects were presented as ways through which the problems of institutional oppression and inefficient service provision could be achieved. The person-centred care model has now come to be considered as best practice in English social care (The Health Foundation, 2016).

### **The landscape of contemporary learning disability social care in the UK**

The Care Act, which came into force in 2014, now provides the legal framework for adult social care and has enshrined in law the individual and wellbeing principle around which all adult social care should be organised (Care Act, 2014). This Act reflects the person-centred approach within contemporary social care support and explicitly indicates how social care has moved away from an institutionalised model where all support is provided by the same people and in the same place. By contrast, the contemporary social care landscape is largely made up of different community services, mostly consisting of private companies and charities providing a range of community-based services to people, either in their own homes or in organisation-owned properties and services. Though local authorities still provide some support, they now mostly commission support through these independent care providers and act as a regulatory body of social care through the Care Quality Commission (CQC).

### **Personal budgets and direct payments**

In the UK, a number of terms are used to describe funding for people with learning disabilities, including consumer directed and self-directed support (SDS). However, they are increasingly referred to as personal budgets and direct payments (Manthorpe, Moriarty & Cornes, 2012; Care Act, 2014). In order to reflect the user-led rather than service-led approach of contemporary support, and in accordance with the Care Act 2014, the financial part of people's support is now paid through personal budgets. People's hours of support are calculated

through a needs assessment, which was introduced on p.22, and is the total amount of money a person's local authority has assessed them as needing to purchase their required care and support. The aim being that these hours are used by the person as and when they wish. This approach to support is based on the principle that people should not be cared for/supported when they do not need to be, as this creates unnecessary dependence on services, thwarting people's ability to become independent (Department of Health, 2010).

A person can choose for their personal budget to continue to be spent in the following ways, out of which they can select one option or a mixture of all: they can ask their local authority or a service provider to continue to manage their funds, which are spent with their involvement; their funds can be moved to a trust, which is managed by their family or carer; finally, they can select to receive their funds as a direct payment, where the money is paid directly to them and they use this to purchase their care and support themselves (Care Act, 2014).

In addition to allocating funds to enable people with more choice, it is also intended that personal budgets and direct payments will recognise the importance of non-service-led support in people's lives, such as family support. Where possible, people are encouraged to employ family members or close friends to support them. It is argued that this is a means of financially recognising private support and it is argued that informal paid support is less expensive than support provided by organisations, which saves people money (Pavolini & Ranci, 2008; Leys, 2001).

### **Supported living**

In terms of housing, the gold standard approach is now considered to be supported living. Indeed, the government's approval of supported living services is reflected in recommendations in the Care Act 2014 that states this should, where possible, be 'the preferred option' (Care Act, 2014). Supported living is defined as small-scale living in properties, either in single occupancy or small group homes, with no more than five, and with like-minded people of a similar age and level of disability (Department of Health, 2010; Wood & Greig, 2010).

Supported living accommodations are also expected to comply with 'Reach: Support for LIVING an ordinary life 2014' (previously Reach Standards in Supported Living, Paradigm, 2002), a set of 11 standards which have been created to 'ensure that supported living focuses on ensuring each person is able to live the life they choose with the same choices, rights and responsibilities as other citizens'.

In supported living the provider organisation (who provides care and support) cannot also own the property where support is being provided, as this is considered to be too similar to institutionalised care. In supported living, the person themselves in effect rents their property/room from a separate housing association, which ensures security of tenure. The expectation is that, by separating support across different organisations, there will be more choice for the person, and where appropriate, their families, to pick the service that best suits their needs (Care Act, 2014).

Other housing services are also available, such as nursing and residential care. However, across provider organisations, where possible, there is an active move towards moving people into supported living (Department of Health, 2001; 2009a). This represents a vision for learning disability social care, which is to continue to filter out those services that were previously under state care, and which are now viewed as representing its failures. This transition has also been evident in the widespread closure of many day centres across the UK (Department of Health, 2010). Day centres are generally considered as having 'made a limited contribution to promoting social inclusion or independence for people with learning disabilities' (Department of Health, 2001: p.76, para.7.21). In this sense, they are not viewed as coordinating with a person-centred approach to living. Nor are they viewed as conducive to supporting people in gaining employment, which, as already mentioned, is one of the central means through which it is hoped that people with learning disabilities will achieve independence and community inclusion (Office of the Deputy Prime Minister, 2005).

## **Safeguarding vulnerable adults**

Social care support in the UK is also governed by procedures safeguarding against abuse, harm and neglect of 'vulnerable adults', which includes adults with learning disabilities (Care Act, 2014). Following the National Health Service and Community Care Act 1990, safeguarding duties were redistributed away from central government and into local authorities' remit. Latterly, in 2000 in England, the No Secrets documents were issued as guidance under section 7 of the Local Authority Social Services Act 1970. This guidance indicated the responsibilities of local authorities to 'investigate and take action when a vulnerable adult is believed to be suffering abuse' (Department of Health & Home Office, 2000). Prior to 2014, local authorities were not legally obligated to follow this. However, with the introduction of the Care Act in 2014, this guidance became a legal requirement.

## **The Mental Capacity Act 2005 and Deprivation of Liberty Safeguards 2007**

Within England and Wales, the introduction of the Mental Capacity Act 2005 (MCA) provided a legal framework for protecting the rights of individuals over the age of 16 who may lack the mental capacity to make one or more decision about their care and treatment. The Act begins with the assumption that the person has the capacity to decide for themselves, and that a decision can only be made on their behalf when it is shown they do not possess capacity to make that particular decision.

Importantly, the Act sets out the following: first, that if a person is unable to make a decision regarding one area of their life, it should not be assumed that they will not be able to do so in other areas. In this sense, determining whether someone has capacity must be made in relation to a specific decision. Second, decisions that are perceived to be 'unwise' by others should not prevent a person from acting on that decision if it is confirmed they have capacity. Third, any decisions that are made on behalf of a person must be done following 'best interests' (a checklist to be followed, which ensures decisions are made with the person in mind), and with the 'least restrictive option' in mind, which ensures the most freedom for the person.

In 2007, the now landmark case, *R v Bournewood Community and Mental Health NHS Trust* (Zigmond, 2009), indicated the need to protect the rights of people unable to speak for themselves in care and treatment settings. Following this, an amendment was made to the MCA, known as the Deprivation of Liberty Safeguards (DoLS) (Department of Health, 2007b). In cases where a person lacks capacity to consent to decisions that have been made about their care, DoLS provides legal protection for vulnerable people by requiring local authorities to grant a legal authorisation to providers of care, which enables them to deprive an individual of their liberty for the period that the care arrangements are in place. This legal aspect of capacity is a highly complex area, which cannot be fully explored in this thesis. However, it is useful to refer to this when thinking about the care and support of people with learning disabilities. In particular, it is useful to reflect on this in the context of the catalogues of abuse and neglect that have taken place within learning disability support over the decades, some of which I discussed at the beginning of this thesis. Such legislation attempts to protect the rights of people with learning disabilities and has been part of a general approach by governments to frame these issues within a human rights context. In 2008, the Joint Committee on Human Rights published the report, *A Life like any other? Human Rights of Adults with Learning Disabilities*. The report outlined its intention to respond to high profile cases that had occurred over the past two years, and which indicated that the treatment of people with learning disabilities was not being provided in accordance with the Human Rights Act 1998. The intention of this report was to raise awareness of this and to make recommendations to health and social sectors:

‘The extent to which the rights of adults with learning disabilities are currently being respected raises fundamental issues of humanity, dignity, equality, respect and autonomy: all key human rights principles’ (p.7).

‘It recommends legislation to ensure that all providers of health and social care are considered public authorities for the purpose of the Human Rights Act and are subject to the duty to comply with Convention rights’ (p.5).



Despite enshrining these rights in law, many people continue to be disempowered by the support they receive, as was shown in the way that the 2011 Winterbourne View scandal revealed itself to be only the tip of the iceberg in how people with learning disabilities had been chronically failed. Indeed, legislation such as the Mental Capacity Act indicates the ways that rights and decision-making powers of people with learning disabilities are fragile and difficult to uphold. This complex history is reflective of the extreme tension that exists in trying to balance freedom and protection for vulnerable people, such as people with learning disabilities.

This idea of balancing freedom and protection brings us back to the contrasting political views discussed in this chapter of whether it is the state or the market who is best placed to enable people with learning disabilities to flourish. These debates themselves of course stem from broader ones relating to the relationship between the state and its citizens. The added complication to this debate in the lives of people with learning disabilities is in the way that their ability to self-govern is limited, to varying degrees, by their condition. Consequently, this raises the following questions: first, to what extent are people with learning disabilities able to self-govern; and second, in what ways do the limits of their ability to do so shape conceptions of their freedom?

## **Chapter conclusion**

In this chapter I have provided an overview of social care policy in the UK. This has included how policies have been shaped by wider social, political and economic philosophies, which have also come to define and shape relations between the state and people with learning disabilities in the context of social care support.

I have described how the move towards using the market to manage the delivery of learning disability social care support emerged, in part, out of a recognised failure of state enterprise to provide services that accorded with social and economic demands and expectations (Johnson & Walmsley, 2010). By the late 1970s, the benefits of universal provision, which had previously defined

nationalised care as a benevolent social institution, had been recast as provider dominated, paternalistic and financially inefficient. As a result of these failings, state-run services were shown to be limited in their ability to respond to people's individual needs (Shleifer, 1998; Johnson & Walmsley, 2010). I also described how, from the 1970s, neo-liberal and disability activist movements struck a chord with one another in terms of their focus on the dangers of overbearing state control over individual autonomy. This shared belief fuelled the idea that institutions should be built around individuals, rather than the other way around, and was a contributory factor in enabling principles of free market capitalism to become transferred into the social care sector (Johnson & Walmsley, 2010). Third Way politics then aimed to give a human face to economic enterprise by balancing it with social policies that aimed to create equality of outcomes for all (Lewis & Surender, 2004).

In chapter two, I will review the previous research that has explored how these philosophies have come to construct particular identities for people with learning disabilities, as well as the implications of these identities for the relationship between people and the state. Emerging from these debates is also the issue of what should and/or can constitute a fulfilling life or good life for people with learning disabilities.

## **Chapter two**

### **Literature review**

#### **Introduction**

Much research has attempted to understand the impact of the reforms that have transformed UK-based learning disability support over the last seven decades. In this chapter, I review the research that has explored and critiqued these transformations, in terms of how policy reforms have been seen to impact the everyday nature of learning disability practice. Debates have revolved around the range of identities that have been constructed for people through the social, political and economic philosophies that have come to shape social care support. In attempting to protect people whilst also empowering them with various kinds of autonomy, the ideological foundations of these philosophies also have implications for whether it should be the state or the market that are best placed to enable people to live fulfilling lives. In reviewing the previous literature relating to this area, I will attempt to determine where gaps in knowledge remain which require further empirical investigation. I end this chapter by arguing that understanding these issues requires in-depth exploration of people's situated experiences.

#### **The multiple constructions of people with learning disabilities**

In attempting to improve the lives of people with learning disabilities, government policies across both the right and left political spectrum have constructed a range of identities which, in differing ways, aim to enable people with independence and community inclusion. These identities include: citizen, consumer, employer, employee and friend. Importantly, these aspirations also include the recognition that people with learning disabilities are vulnerable and so in need of protection.

Within contemporary learning disability social care, these identities are expressed through New Labour's 2001 White Paper, *Valuing People: A New strategy for*

*Learning Disability for the 21st Century* (Department of Health) which sets out a vision of providing 'new opportunities for people with learning disabilities to lead full and productive lives as valued members of their local communities' (p.22). In the years since the publication of *Valuing People*, governments have published several social care documents which have contributed to shaping service delivery, including *Putting People First* (Department of Health, 2007a), which sets out a commitment to offering individual budgets for people, as well as the Care Act 2014, which now provides the legal framework for all adult social care. These documents, along with *Valuing People*, were intended as 'policy blue prints', in that they set out the overall conceptual plans for the style of services to be delivered. Crucially though, *Valuing People's* stance towards particular kinds of independence and inclusion has remained fundamentally influential to learning disability care and support into the 21<sup>st</sup> century (Hassan, 2017).

### **Active citizenship and purchasable services**

Contemporary social care support is largely defined by the way it is made up of a range of services which are mainly regulated by the government, but are provided by independent sectors. Managing the delivery of social care support through market mechanisms is based on the rationale that self-interest spurs the service provider into meeting consumer needs. As well as ensuring that the provider stays afloat and continues to make a profit (Clarke, 2006), it is expected that people with learning disabilities (and their family/significant others) will be more likely to gain access to the services they want for a reasonable price.

Under a market-style system, what would be the local government's role of central mediator between the state and service users is replaced with the person themselves (and their family/significant others), who is then directly given the purchasing powers. Accordingly, the principles of the market allow users of services to become a part of the 'consumer society' (Clarke, 2006). The idea behind this is that becoming consumers empowers recipients of services as partners in, rather than passive recipients of, the management and delivery of their received services (Campbell, 2001; Mansell & Beadle-Brown, 2004; Department of Health, 2009a; Department of Health, 2010). In this sense, as was

set out in *Valuing People*, individuals take on 'active citizenship' in the management and receipt of their support (Shleifer, 1998; Department of Health, 2001).

The perceived benefit to organising relations in this more direct way is that it will provide recipients of services with the satisfaction of being in control of what they purchase and of spending their money as they wish. Furthermore, it is expected that the responsibility of being the direct purchaser will mean that people will be more incentivised to seek out services that offer most value for money (Demos, 2008). In turn, reputational mechanisms then act as internal market regulators and indicators of what services should be available – service providers that are not value for money and do not meet the needs and preferences of consumers are less likely to be purchased and to survive as businesses (Giddens, 1998). Thus, the ability for consumers to 'exit' and to have their preferences and 'voice' heard forces services into a state of a constant competitiveness and innovation (Shleifer, 1998; Department of Health, 2007a).

A legacy of *Valuing People's* ideas about 'active citizenship' can be seen in personal budgets and direct payments. By directly receiving funds required to pay for their support, the person effectively becomes the employer with responsibility for selecting their own support (Department of Health, 2009a). The expectation is that this will encourage the person to purchase the services that they want and need, which in turn increases efficiency and reduces unnecessary losses for the provider (Department of Health, 2010). Furthermore, within the 'mixed economy' of service provision, the person is enabled with greater freedom of choice as they can select from different combinations of local authority, non-profit, for-profit organisations, as well as support from family and significant others to meet their needs (Department of Health, 2001).

Indeed, incorporating support from family and significant others as a purchasable service has been viewed by recent governments as being of importance (Department of Health, 2007a). The expectation here is that family and significant others will be familiar with the person's needs and more inclined to ensure they are providing high quality support in caring and compassionate ways

(Department of Health, 2007a). Importantly, it is not intended that this kind of support should be viewed as a total replacement to professional support. Rather, the intention is that it enables the state to recognise the social and economic value of 'private relationships' in people's lives, such as those with family and friends (Pavolini & Ranci, 2008; Department of Health, 2010).

Advocates for a market-style approach to managing social care delivery also insist that there is a distinct difference in the way services are bought and sold in this context with that of how commodities are exchanged under free market capitalism more generally. This is because with commodities that are bought and sold, no social bond develops between the buyer and producer. However, it is argued that this is not the case with services, such as ones which involve caring activities, because the producer – the care giver – and the buyer – the recipient of care – still meet face-to-face and so have the potential to develop precisely the kind of trust and mutual respect that the market is said to hinder (Buntinx, 2008). Arguably too, the desired goals of the state in the context of social care – in which users of services should be empowered to make choices and take control of their support – can still be achieved, as the state still retains control over regulation of services (Shleifer, 1998).

### **Citizenship and inclusion remain out-of-reach**

It is well recognised that, as the first learning disability white paper in 30 years, *Valuing People* was a much-needed policy attempt at improving services and opportunities for people with learning disabilities (Burton, 2004). Furthermore, it is true to say that in the decades following New Labour's policy reforms, some people have benefited from the *Valuing People* policies, which intended to empower users of services with access to what is described as a 'normal' life. This can be seen, for example, in terms of the number of people with learning disabilities now living in the community (Burton, 2004), as well as people's increased access to relationships with others, including sexual relationships (Rogers, 2009). Despite these efforts, however, research shows that aspirations of independence and community inclusion still elude many people with learning disabilities (Riddington, Mansell & Beadle-Brown, 2008; Simpson & Price, 2009).

In fact, for many people, the reverse has been true in that individualised and community-based support has brought with it the unintended consequences of stigmatisation, loneliness and social isolation (Scull, 1983; Brown & Smith, 1992; Simpson & Price, 2009; Johnson & Walmsley, 2010; Scior & Werner, 2016). Despite a wide range of services made available for people with learning disabilities and the fact that levels of health, wellbeing and economic status have improved since the closure of long-stay hospitals (Kinsella, 1993), compared to people without learning disabilities, they still feel the impact of inequalities in these areas (Mencap, 2007; 2012; Michael, 2008). It is important to point out too that these figures do not consider individuals who are not known to state services, and so actual numbers of people experiencing various forms of inequalities are likely to be higher than those reported (Tinson, Ayrton, Barker *et al.*, 2016).

### **Empowering people with learning disabilities as consumers?**

It has been argued that, because of the way that social relations work in social care, the individual rationality of the market does not translate successfully into this context. Over the last 20 years, there has been increased debate about whether the rationale of the market is best placed to organise and provide this kind of service (Chomsky, 1999; Blank, 2000; Saad-Filho & Johnston, 2005; Clarke, 2006; Plehwe, Walpen & Neunhöffer, 2006; Lymbery, 2010).

For example, the rationale that the market enables people with learning disabilities to form a direct relationship with services managing their support has been argued as problematic. As I described at the beginning of this thesis, the experience of learning disability is wide ranging, with some people living independently with minimal hours of support per week, whilst others require 24-hour support for the duration of their lives (Department of Health, 2001; Rapley, 2004). However, the cognitive effect of having even a mild learning disability is such that even people considered to be independent tend to require help to manage aspects of their support, such as their funding and purchasing of support (Morris, 1997).

Furthermore, despite changes in the Care Act 2014, which indicate the importance of independent advocates to support people to purchase their services, such as personal budgets and direct payments, a lack of available funding within local authorities has meant that many people remain without access to independent advocates for this support (Hall, 2011). Moreover, when people do have personal budgets and direct payments, it tends to be provider organisations and/or family members who manage them (Hall, 2011). In this sense, because people are likely to require support when deciding on and purchasing their services, the 'direct' relationship that is described as taking place between the consumer and provider under a market style system is compromised.

The fact that people with learning disabilities tend not to be able to use their own initiative as consumers in the market place is problematic as it compromises an essential element of individual flourishing that is said to take place through relations regulated by the market. Therefore, positioning people with learning disabilities as decision-making consumers empowered with economic freedoms in the free market could be unrealistic (Hartman, 2005). Ultimately, this calls into question the neo-liberal and, in part, Third Way approach of using the market to manage social relations within social care services.

### **Reducing care work to task-based activities**

Critics also argue that a mechanism of market relations – to create cost and time efficiency with a view to increasing profit – can negatively impact upon the quality of support that people receive in social care. It was pointed out above on p.49, that under this system, support workers and people with learning disabilities continue to meet face-to-face as care is delivered and received, which allows them to act with discretion and in spontaneous ways (Wastell, White, Broadhurst *et al.*, 2010). Yet, it has also been argued that even if taking place face-to-face, the focus on cost and time efficiency can mean that caring practices are at risk of becoming task-based activities (Harris, 2003). If staff are treating their work in these ways, rather than the complex emotional labour that it is, there is a danger



that they may become emotionally detached from their work and begin to objectify the people they support (Clegg, 2008; Reinders, 2008).

Issues relating to how care working environments can be negatively affected by these kinds of efficiency-related standards was discussed on the Radio 4 programme, *Analysis* (Caring in the New Old Age, 2015). The actual context of care work being discussed in this programme was that of care for older people; however, arguably there are similar emotional complexities involved in caring for these different population groups in a similar landscape of contemporary social care (Bigby, 2002). The programme's presenter drew on a 1959 landmark study of nursing by Isabel Menzies Lyth, who found that in attempts to protect nurses from the emotional stresses present in their work, hospitals organised nursing work in a task-based manner (Menzies, 1960). This encouraged nurses to emotionally detach themselves from their work and, in turn, allowed hospitals to continue to function. However, Lyth showed there were downsides to this. As well as nurses not being offered professional space to fully come to terms with the anxieties they experienced through their complex work, this emotionally detached approach to care stilted the ability of nurses to relate to their patients in human ways, which meant that they were at risk of objectifying them. Paradoxically, this had a direct impact on efficiency and performance rates, with high levels of anxiety amongst nurses, high staff/patient turnovers as well as poor patient recovery rates. In this, Lyth described how:

'The social structure of the nursing service is defective not only as a means of handling anxiety, but also as a method of organising its tasks. These two aspects of the situation cannot be regarded as separate. The inefficiency is an inevitable consequence of the chosen defence system' (p.118).

Lyth's work illustrates the effects of prioritising organisational aims over individual needs. The programme's presenter went on to connect Lyth's findings with contemporary social care, in which independent organisations focus upon cost and time efficiency. The argument was that this may be negatively impacting the ways that care staff are able to support people they look after. Here, the presenter

also incorporated other issues relating to social care – that of untrained and low-paid staff – who are arguably less likely to either have the skills or incentive to provide care in respectful and compassionate ways:

“In social care today we have a system that puts low-paid individuals, with hardly any training or support, into emotionally stressful caring jobs under significant time pressure. In these circumstances, some people may naturally adopt the kind of objectification Lyth observed as a coping strategy” (Caring in the New Old Age, 2015).

## **The uneasy relationship between conceptions of community inclusion and economic empowerment**

### **The problem with Care in the Community**

In addition to the problems associated with free market mechanisms, the social theories of normalisation and social role valorisation (SRV) have also been called into question on the grounds that they paint idealised pictures of community life and focus strongly on encouraging people with learning disabilities to live ‘normally’ to ‘fit in’ with the rest of society (Bayley, 1991). Such ideas are now considered by many activists to be oppressive of people’s individuality (Johnson and Walmsley, 2010). Accordingly, normalisation and SRV have been superseded by the social model of disability, which has focused on citizenship and human rights as ways with which to empower people with learning disabilities (Johnson & Walmsley, 2010). Despite this, however, it is argued that learning disability policy continues to present the community as an idyllic world in which people with learning disabilities would be welcomed with open arms by their non-disabled counterparts:

‘The utopia painted by VP [*Valuing People*] ... sees people making choices about activities in pleasant neighbourhoods, with plentiful community resources. They are supported in this by their own staff, which they employ and who work to their specification. They are likely to be in work, and to have friendships and relationships, mostly with

nondisabled people. Somewhere in all this there is the notion of independence' (Burton & Kagan, 2006: p.305).

Combined with this idealised version of community living, the *Valuing People* documents also reflect values promoted through the social model of disability. They present high aspirations for citizenship for people with learning disabilities, as indicated in the following excerpt from *Valuing People Now* (Department of Health, 2009a), which is the 2009 follow-up to the 2001 *Valuing People*:

'For all of us, rights come with responsibilities. Citizenship is also about contributing to society, in whichever way we can. People with learning disabilities have traditionally been viewed as recipients of care and of services. But they, too, have a role to play as contributors. Wherever possible, people with learning disabilities should be supported to work, pay taxes, vote, do jury duty, have children, and participate in community activities or faith groups. Many people with learning disabilities in using direct payments or personal budgets will contribute to the economy by becoming employers. All these things benefit the wider society' (p.32, para.16).

Despite its compelling political force, however, the social model of disability has also fallen under scrutiny. As I have mentioned, the rights-based approach that has fuelled the social model movement has come to situate itself within a framework of citizenship and human rights, arguing for disabled people to be given equal access to these rights in the same ways as non-disabled people (Shakespeare, 2006). Yet, scholars have pointed out that in accepting the social model's stance – that it is society that disables individuals and not their impairments – there can be a tendency to take this approach too far and to reject entirely biomedical definitions of disability. This can fail to acknowledge the reality that people's material impairment(s) will, to varying degrees, affect their ability to function in the world (Morris, 1991; Crow, 1992; French, 1993).

### **Employment: an unattainable social good**

An example of how the social model has influenced notions of disability can be seen in policy with a focus on paid employment for people with learning disabilities. Returning to the Burton and Kagan extract above, on pp.53-54 (2006: p.305), the mention of work is reflective of aims by recent governments to present paid employment as an aspiration that should be central to people's lives. Indeed, *Valuing People* (Department of Health, 2001) and *Valuing People Now* (Department of Health, 2009a) both include a strong emphasis on employment for more people with learning disabilities:

‘All people and their families [should] have a fulfilling life of their own, beyond services ... this includes supporting more people with learning disabilities into paid work, including those with more complex needs’  
(Department of Health, 2009a: p.83).

This focus on employment represents a general effort by recent governments to encourage people with learning disabilities out of day centres and into paid employment (Department of Health, 2010). For some, this could be read solely as part of a neo-liberal agenda that views economic dependency on the state as undesirable and representative of a lack of individual responsibility (Burton & Kagan, 2006). However, taking the somewhat cynical view that the push to get people with learning disabilities into work relates to the government's global economic agenda arguably fails to acknowledge the more complex ways in which employment is presented in policy. As the extract from *Valuing People Now* presented on p.54 shows (Department of Health, 2009a: p.32, para.16), employment as an economic social good, is presented alongside other social goods, such as social identity, inclusion and citizenship. Instead, rather than indicating a global economic agenda, the presentation of employment could perhaps more credibly be viewed as indicative of the uneasy relationship that exists between neo-liberal/Third Way economic policies and disability social theories of social identity, inclusion and citizenship (Burton & Kagan, 2006: p.303). This is evident in another extract from *Valuing People Now*, which makes distinct associations between employment and a sense of self:

‘Work defines us: what will you be when you grow up? What do you do for a living? These are questions we all face from others when people want to get to know us. But they are questions seldom directed towards people with learning disabilities. Because so few people with learning disabilities do work, there is no expectation from others that they can, and consequently little is done to offer them the opportunity’ (Department of Health, 2009: p.86, para.3.43).

The document goes on to state that paid work for people with learning disabilities will only be attainable once society begins ‘to believe work is a genuine possibility’ for people with learning disabilities (Department of Health, 2009: p.87, para.3.45). This distinctly echoes the social model theory that it is society that limits people from flourishing rather than the material restraints of their impairment.

The notion of work as contributing to a sense of self is arguably a valid one through which governments are genuinely attempting to find ways to include people with learning disabilities into society. Indeed, there is evidence to show that some people with learning disabilities would like to work and view this as a means by which they are able to express themselves and feel ownership over their lives (Hall, 2005). However, presenting the notion that these kinds of social aspirations are attainable through paid work has been argued as potentially damaging for people for whom this kind of work is not likely to be an option (Hall, 2005).

Importantly, the rhetoric of promoting employment as real possibilities for people with learning disabilities does not reflect research which shows that many people with this condition are unable to enter into the work place as productive employees on the same terms as people without learning disabilities (Verdonschot, de Witte, Reichrath *et al.*, 2009). Despite the resources that have been put into employment support and training for people with learning disabilities, many remain out of paid work. Moreover, for those that can gain paid employment, this labour tends to be unskilled and low-paid (Redley, 2009). Access to only low-paid work means that for many people employment is

‘insufficiently rooted in economic reality’, in that it rarely provides the same kind of economic security as welfare benefits (Redley, 2009: p.497).

When thinking about the ways in which governments have been influenced by the social model of disability when promoting employment within policy, it is worth reiterating here that the social model theory was originally championed for people with physical disabilities. This is important as the experiences of physiologically impaired people arguably differ from individuals who experience cognitive impairments. As such, understanding the ways that society responds to these impairments and how this impacts people will also be different. For instance, although individuals with physical impairments do experience social stigma, the social model movement has tended to be defined by its rallying against limitations caused to people by the physical environment, for example, inaccessible workplaces and transport systems. Conversely, although people with learning disabilities may indeed experience difficulties with physical environments, their exclusion also relates to aspects such as difficulties in learning new skills, as well as difficulties in developing relationships with people without learning disabilities (Shakespeare, 2006). Crucially, there is a huge difference in altering physical aspects of environments to that of altering their relational elements, for example, in the workplace. To this end, it has been argued that the social model’s attempt to emancipate cognitively impaired people in the same way as physically impaired people is flawed (Shakespeare, 2006).

The emancipatory potential of the social model is compromised further still when considering the activist element of the theory. Physiologically impaired individuals tend to have the means to self-advocate, which is a crucial aspect of self-empowering political activism. For people with learning disabilities, self-advocacy is more complex. Although there are many individuals who do engage in this, and many others who are able to express their needs and wants, it is difficult to get away from the fact that people’s cognitive impairments do, to varying degrees, obstruct their ability to independently express themselves within a political arena (Redley & Weinberg, 2007). Although, here the social model would argue that the fault and failings are with society for not having the tools to enable people with cognitive impairments to have their voices heard, the fact remains that asserting

rights around citizenship is objectively harder to achieve for people with learning disabilities.

### **The ethics of care: a challenge to individual autonomy**

There have been attempts to move away from thinking about the lives of people with learning disabilities in terms of independence and self-sufficiency, as characterised by the social model of disability (Johnson, 2013). Recognising that care and support plays a central role in the lives of many people with learning disabilities, the ethics of care approach places these caring relationships at the centre and recognises them as inherently meaningful in and of themselves (Clegg, 2000; 2015; Reinders, 2010). To this end, it is 'the relational and convivial aspects of inclusion and participation' that are of importance rather than independence and self-sufficiency (Redley, 2009, p.497; see also Dowse, 2009).

In the context of care and support practices, the theory of care ethics has also been used to present a way of providing ethical care, in which there is a focus, not solely on abstract ideas about doing the right thing, but also on thinking about how to respond to the person in the unique context of the care dynamic (Clegg, 2004). This concept of care involves developing engaged relations between staff and people being supported, and practices of personal and professional reflexivity by staff (Clegg, 2004). The feminist scholar, Eva Kittay, has described care ethics as a way of moving beyond what is increasingly being seen as the dichotomy between promoting autonomous living on one hand and paternalistic caring practices on the other. Kittay has called for a move towards a notion of relational autonomy, which acknowledges that all individuals are situated in a 'matrix of relationships' of dependencies and interdependencies on each other (Kittay, 2007).

It has been suggested that a care ethics approach might be achieved in professional support when it is provided in combination with 'pragmatic legal regulation 'at arm's length''. The argument here is that this would then ensure regulation of services, but within the context of 'forward-thinking, imaginative support' in which staff play a crucial, rather than cursory role in the provision of

support (Dunn, Clare & Holland, 2010: p.157). The care ethic approach has, however, received criticism for being too idealistic in its expectation that, with less abstract regulation and with the 'right' training, caring relations are more likely to gravitate towards ethical behaviour (Hugman, 2005). The criticism being that this approach does not alter the inherent properties of the imbalance of power in relations between carer and caree, but instead can serve to mask these properties, which can lead to paternalistic caring practices, or even abuse (Emanuel & Emanuel, 1992). Given this, it could be said that this kind of ethical framework presents too much of a risk for vulnerable individuals, such as people with learning disabilities, as it expects too much of the people providing support and is difficult to enforce.

### **Previous empirical research**

As the above review of literature indicates, much of the debate that has taken place over the last few decades regarding learning disability social care support has questioned whether the state or independent sectors are best placed to provide services in this context. Within this, there has also been debate about the various ways that people with learning disabilities have been constructed through identities, including citizen, consumer, employer, employee, friend and vulnerable adult. This illustrates the complexities and tensions that exist around notions of how people with learning disabilities might best be supported to live a good life.

In terms of thinking about how this good life might be explored empirically, given that care dynamics are central aspects of many people's lives, it is these social relations that have been pinpointed by many researchers as key to understanding both what is going on in the context of everyday support, as well as determining how these relations might work in ways that improves quality of life for people with learning disabilities. In determining this quality of support, many studies have sought to consider under what conditions the balance between the key aspects of contemporary social care support – autonomy and protection – might be balanced (see for example: Schalock, 1990; Bannerman, Sheldon, Sherman & Harchik, 1990; Crichton, 1998; van Hooren, Widdershoven, van den Borne &



Crufts, 2002; Graham, 2010; Robertson & Collinson, 2011; Gill & Fazil, 2013; Petner-Arrey & Copeland, 2014; Hollomotz, 2014).

Perhaps it has partly been due to the historical positioning of learning disability within bio-social disciplines, such as medicine, nursing, psychiatry, psychology and social work/care that has led to research conducted in this area tending to align with the ontological and epistemological orientations of these disciplines; those rooted in objective stances of reality and quantitatively-driven research approaches, such as questionnaires, clinical observation and cognitive assessments. Furthermore, the ways that people's cognitive impairments impact their lives has also arguably made including them in immersive qualitative approaches more challenging. For instance, many people with learning disabilities can experience difficulty in verbally accounting for themselves which can mean that they are excluded from methods such as interviews (Owen, Hubert & Hollins, 2008). Additionally, determining whether people with learning disabilities understand what has been asked of them in the research context, especially with methodologies that are emergent and unpredictable, raises complex ethical issues relating to consent. Finally, there is also the issue of the extended length of time that is often required to include the views and experiences of people with learning disabilities, which is not necessarily possible within the time constraints of some research projects (Stalker, 1998).

Given these factors, there exists a large body of research made up of quantitatively driven methodological approaches. These studies have used an array of quantitative measures to investigate various aspects of learning disability social care support. Such measures have included comparative assessment tools and organisational culture assessment tools to evaluate quality of life and staff performance between residential settings (Gillett & Stenfert-Kroese, 2003); a Goal Rating Scale to measure aspects of health and wellbeing amongst people with learning disabilities living in residential care (Adams, Beadle-Brown & Mansell, 2006); and proxy questionnaires with support staff to ascertain the success of Active Support training on skill development for people with learning disabilities (Koritsas, Iacono, Hamilton & Leighton, 2008).

Elsewhere, a number of other studies have assessed Active Support by using quantitative measures to count frequency of interactions amongst staff and people with learning disabilities in care/group homes (Felce & Perry, 1995; Messent, Carlton & Long, 1998; Messent, Cooke & Long, 2000; Felce, Bowley, Baxter *et al.*, 2000; Mansell, Elliott, Beadle-Brown *et al.*, 2002). Active Support is a method designed for staff to enable people to engage more widely in their daily lives. Its core components include, supporting people to interact with others; developing activity support plans to organise people's lives; and keeping a record of what has been achieved (Jones, Perry, Lowe *et al.*, 2011). The argument for using Active Support as a method for improving aspects of care, such as increasing frequency of interactions between staff and people being supported, is indeed premised on the well-established claim that increased staff/resident interaction leads to improvements in quality of life for adults with learning disabilities in these settings. In this sense, measuring the use of methods such as Active Support can be useful in regulating staff behaviour. However, where these approaches could be viewed as methodologically weak is in their failure to indicate the nature of these interactions. It is here where qualitative approaches become useful as they allow researchers to collect this more nuanced information relating to the nature of interactions.

Indeed, there are studies that have used qualitative methods to explore inter-relational dynamics between support staff and people with learning disabilities with a view to understanding the complexities and nuances of support in this context. Tony Holland and Josephine Wong (1999) used clinical case studies to explore the legal and ethical issues and dilemmas involved in supporting and/or intervening in the lives of adults with Prader-Willi syndrome (PWS). This is a genetic condition, where satiety is compromised, which can lead to overeating. Problematically, PWS is typically accompanied by a mild learning disability, which causes complications in managing the compulsion to eat. Holland and Wong specifically address the dilemma of whether to allow people with PWS to make decisions that are knowingly harmful, such as around eating, or to stop them from making these decisions in order to keep them safe. They argue that, if someone does not have the capacity to understand the consequences of their dietary decisions, it will be in their best interests for others to take these decisions on

their behalf. Importantly though, they argue that because each individual's eating behaviour is different, the nature of the decisions taken will similarly need to be context specific.

Elsewhere, Treena Jingree and W.M.L Finlay (2008) conducted semi-structured interviews with support staff working in services for people with learning disabilities to explore the ways these staff talked about giving or withholding choice and control in this context. Questions in the interviews were drawn from relevant issues raised in the White Paper, *Valuing People*, (Department of Health, 2001). From their interviews with support staff the authors suggest that to justify why it was not possible to enact the objectives of enabling people with learning disabilities with autonomy, as set out in *Valuing People*, support staff would engage in acts of what the authors describe as 'practicalities talk'. Through this 'practicalities talk' the possibility of achieving the ideals of choice would subsequently be nullified as impractical. This was illustrated for instance when 'staff constructed service-users as incompetent and vulnerable [which] served to justify why choices could not be facilitated in some situations' (p.723).

### **More in-depth methodologies: ethnography**

Studies such as Holland and Wong's (1999) and Jingree and Finlay's (2008) have yielded interesting and important findings. They have also raised pertinent questions regarding the nature of social care support and relational dynamics between support staff and people with learning disabilities. Yet, I argue that these approaches remain somewhat one-dimensional in that they only reveal views and experiences in singular ways, and they also tend to be situated out of context of people's everyday lives. For instance, although Jingree and Finlay's study shows the ways that staff described what they did in the context of support, through interview alone it was not possible to know how staff behaved when they were with people they were supporting. Furthermore, these approaches rely heavily on people's ability to account for themselves verbally, which again excludes many people with learning disabilities.

Crucially, an ethnographic approach would focus upon exploring the inter-relational dynamics of people with learning disabilities and their support staff within the everyday context of support. It is through exploring relations in situ that examination of those complex areas of social life – that can be evasive to less immersive research approaches – are made more possible. Thus, through the kind of deep immersion afforded by ethnography, it may be possible to develop an idea of how people in these settings relate to each other, which in turn may provide insight into how this support could be better provided.

There is an active, albeit small, number of learning disability researchers utilising ethnography. Importantly, as well as capturing the complex practices and relations that make up their life worlds, these researchers also seek to include the views and experiences of people with learning disabilities themselves. Indeed, as I have already mentioned above, the difficulties people with learning disabilities can experience in accounting for themselves contributes an added layer of complexity when attempting to interpret their lives through a research context. Crucially, because ethnography does not rely solely on individuals to provide verbal accounts of their views and experiences, the other ways in which they may express themselves can be captured through ethnography's holistic approach of participant observation.

It is important to point out here that ethnographic research in this area does have some history. Several studies have utilised this approach in order to reflect the need to develop a deeper understanding of the complex relations that make up the lives of people with learning disabilities and the support they receive. Robert Edgerton's classic study, *The Cloak of Competence: Stigma in the lives of the mentally retarded* (1967) was, at the time, novel in its approach of using ethnography to understand social stigma in the lives of people with learning disabilities from their perspectives. Edgerton's study, which I will discuss below, is now seen as a watershed moment in learning disability research. Since the 1960s, it has opened and broadened the range of methodological possibilities for researchers working in this area (see also: Bercovici, 1983; Goode, 1984).

### **Social stigma and binary definitions of disabled and non-disabled**

More recently, the social stigma of Edgerton's study has been explored by Andrew Jahoda and colleagues who employed an ethnographic approach to understand first-hand how people with learning disabilities experience living with social stigma. Human experiences of stigma are, in themselves, difficult phenomena for researchers to capture. Yet, attempting to do this with individuals who, to varying degrees, can experience difficulties in verbally articulating their experiences increases the challenge to achieving this.

To overcome these barriers, in addition to spending six months conducting semi-structured interviews with participants, their families, carers, and other professionals involved in the participants' support, participants were also given disposable cameras and/or video cameras with which to record their own lives. In using a naturalistic approach to understand these complex experiences, Jahoda and colleagues could gain a rich, in-depth picture of the lived realities of people with learning disabilities, one that arguably could not be achieved through methods such as questionnaires and quantitative assessments (Jahoda, Wilson, Stalker & Carney, 2010). Importantly, in their conclusions Jahoda and colleagues point out that the people involved in the research were not 'particularly talkative, nor able or willing to provide elaborate accounts about their lives' (p.531). It was in fact through the other methods of photographs and video diaries that the authors were able to interpret the most nuanced understandings of how stigma was experienced.

In the case of one individual, Jahoda and colleagues show how his desire to seek acceptance as part of a peer group was rooted in a need to 'break out' of the stigmatised identity of an isolated person with a learning disability that had come to define him. Yet, at the same time, he experienced anxiety about the possibility of being rejected by the social group of which he was seeking to be a part (p.530). Elsewhere, another person's experiences were heavily shaped by conflicting feelings of both 'injustice and anger', as well as a sense of acceptance at being defined in stigmatising ways by her mother (p.531). In interpreting these ways of making sense of stigma, Jahoda and colleagues draw upon Erving Goffman's theory set out in his book, *The Presentation of Self in Everyday Life* (1959), which

describes the way in which people enact a performance, akin to a dramatic performance, to 'get by' in everyday life. In this performance, people alter their behaviour in response to others' reactions in the hope of being accepted by their 'audience'.

Elsewhere, Goffman also explored how stigma is experienced in his ground-breaking book, *Stigma: Notes on the Management of Spoiled Identity* (1963). Here, Goffman uses the term 'passing' which he describes as the process people engage in to ensure 'the management of undisclosed discrediting information about self' (p.42). As such, when an individual has something about themselves that they and/or others consider to be discrediting, they will deliberately hide their 'invisible stigma' in order that they might be accepted as normal by those around them. For the person doing the concealing, this involves constant work, through fabrication, concealment and discretion, to cover the stigma and avoid being found out by others.

Goffman's concept of 'passing' can be seen to be echoed in Robert Edgerton's, *The Cloak of Competence: Stigma in the lives of the mentally retarded* (1967), which I introduced above. Similarly to Goffman, Edgerton explored the experience and sociological impact of stigma amongst people with disabilities. Edgerton's study, however, focuses specifically on the lives of men and women with learning disabilities who he followed after they had vacated a Californian institution in the 1960s. Edgerton describes how these men and women were starkly aware of their difference in relation to non-disabled people, and that it was not possible for them to 'shake' off or fully disguise their difference, which was something that forever haunted them. It is for this reason, Edgerton says, that the men and women 'lie' and 'cheat', because they were desperate to gain entry into the 'normal' world (p.209). Furthermore, the lack of 'competence' of these men and women also meant that they continued to require support from others while attempting to gain entry into the 'normal' social spheres of which they wished to be a part. Edgerton's work was ground-breaking in illustrating how the people with learning disabilities with whom he spent time were aware of their difference in relation to others and because of this desperately sought to disguise these differences to reduce embarrassment and social exclusion. A poignant question

both Goffman and Edgerton's forms of 'passing' ultimately raise is whether people with learning disabilities can ever 'pass' in these ways.

Edgerton and Goffman's studies were also both precursors to theories of normalisation and social role valorisation (SRV) in that their theories on the social experience of stigma shone a light on the different worlds that non-disabled people and disabled/stigmatised people inhabit. In doing so, this revealed the binary between experiences and conceptions of 'disabled' and 'non-disabled'. It has been argued that this binary continues to be reinforced in contemporary learning disability policy. This echoes the criticisms already described about disability social theories which, in using such vague soundbites of 'the community' and 'ordinary living' as ways to define inclusion (Wolfensberger, 1998), set vague – and as a result unrealistic – expectations about what this means for people with learning disabilities and those who support them (Johnson & Walmsley, 2010).

### **Institutionalisation**

Goffman and Edgerton's studies indicate how naturalistic empirical approaches to understand people's lived experiences of social stigma provide rich and in-depth accounts of people's lives. Goffman latterly went on to explore other aspects of exclusion, in the form of institutionalisation. In his 1961 book, *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*, he looked at the lived experience of the institution. Here, Goffman describes life outside institutional living as:

'a basic social arrangement in modern society [in which] the individual tends to sleep, play, and work in different places, with different co-participants, under different authorities, and without an overall rational plan' (Goffman, 1961: p.17).

This is contrasted with the 'total institution', which is:

'a place of residence and work where a large number of like situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life' (p.11).

In describing institutional living as a wholly segregated and closed experience, Goffman (1961) vividly portrays the dangers of this and the ways that social relations are negatively impacted by institutions. He describes how, bound up in the daily toil of mass washing, dressing, sleeping and eating, people's individuality gets stripped away, which encourages 'batch living'. Goffman uses ethnographic accounts taken from different institutions to show the dehumanising effect of running services on a big scale:

'Once the inmate is stripped of his possessions, at least some replacements must be made by the establishment, but these take the form of standard issue, uniform in character and uniformly distributed. The substitute possessions are clearly marked as really belonging to the institution and in some cases are recalled at regular intervals to be, as it were, disinfected of identifications ... As suggested, the institutional issue provided as a substitute for what has been taken away is typically of a "coarse" variety, ill-suited, often old, and the same for large categories of inmates' (Goffman, 1961: pp.18-19).

### **Deinstitutionalisation**

Despite the significant ways that institutional structures have been shown to negatively impact on people's social relations, there have been more recent ethnographic studies that have similarly identified how, even after deinstitutionalisation and relocation into the community, the lives of many people with learning disabilities continue to be dogged by institutionalising forces and oppressive power dynamics. In returning to the more contemporary canon of ethnographic work in this area, Kelley Johnson (1998) conducted a study in an Australian long-stay hospital, in which she followed a group of women as they were moved out of the hospital and into the community. In her study, Johnson



argues that the move into the community did not improve the women's lives because they continued to be 'swamped by the existing discourse which constituted the women as objects' (Johnson, 1998: p.186).

Similar ethnographic studies have been conducted in the UK by Jane Hubert, Sheila Hollins and colleagues (Hubert & Hollins, 2007; 2010; Owen, Hubert & Hollins, 2008). Here, they spent 15 years using ethnographic approaches to explore the effects of deinstitutionalisation among men and women with learning disabilities. Spending time with these men and women in order to 'get to know [them] and the nature of their daily lives' (Owen, Hubert & Hollins, 2008: p.220), Hubert, Hollins and colleagues also argue that leaving the physical boundaries of the institutions had not improved people's lives because they 'continued not to be acknowledged as unique individuals, who have pasts, close relationships, clear preferences, abilities and rich emotional lives' (Owen, Hubert & Hollins, 2008: p.221).

These above studies indicate something important about power in the care and support of people with learning disabilities. Although Goffman shows that the physical form of big scale institutional living negatively impacts upon interpersonal relations, later studies of deinstitutionalisation by researchers such as Johnson and Jane Hubert, Sheila Hollins and colleagues, indicate that simply removing the material structures of these institutions does not necessarily dissolve power in these contexts, but instead causes it to morph into other forms.

### **Discrepancy between policy and practice**

In addition to exploring people's lives following deinstitutionalisation, ethnography has also been used to understand the impact of defining people with learning disabilities as legal citizens with rights. Tim Clement and Christine Bigby's book, *Group Homes for People with Intellectual Disabilities* (2010) covers an Australian-based project in which the authors conducted a three-and-a-half-year-long study using ethnography and action research to explore five group homes for adults with severe learning disabilities. The justification for this research was, in part, made on the grounds that these methodologies have 'rarely been used to investigate group homes' (Clement & Bigby, 2010: p.35).

Clement and Bigby's study is set against a backdrop of evidence which shows that these types of accommodation tend to replicate institutional conditions and, as a result, are increasingly considered to be outdated. To this end, group homes are being superseded by supported living, a service which is considered to be 'more capable of meeting consumer needs and having the potential of providing a better quality of life' (LaVigna *et al.*, 1994: p.89, cited in Clement & Bigby, 2010). In this sense, services such as supported living are an attempt to legally re-situate people with learning disabilities as 'private citizens living in their own homes'. The aim here is that these legal requirements will begin to impact on the social behaviour of services and staff, who will learn to respond to the people they support in the same ways they would respond to non-disabled people.

In the foreword to this book, Jim Mansell summarises its thesis as the problems associated with using a rights-based approach to empower people with severe learning disabilities. He describes how the study addresses the disparity between the presentation of individuals with severe learning disabilities as legally empowered citizens with the reality that 'people with the most severe intellectual disabilities are never in the position to make informed choices themselves about where they live, who they live with, or how they are supported to live their lives' (Mansell, 2010: p.12). From this, Clement and Bigby argue that the reasons people living in group homes do not live as good a quality of life is because of the influence that policy makers and general management have on everyday practice, whose conception of how people with severe learning disabilities live is far removed from the actual reality. In using ethnographic methods to explore this disparity between policy and practice, Mansell states that 'what this book does, for the first time, is to show how these factors play out in the lives of people with intellectual disabilities and the staff who support them' (Mansell, 2010: p.13). Through these methods, Clement and Bigby have been able to illustrate how 'staff struggle to find a way through the lofty goals of community living, the substantial impairments of the individuals they support and the context provided by the organisations that employ them' (Mansell, 2010: p.13).

Other in-depth qualitative studies have also explored the discrepancy between policy and practice, in terms of how certain organisational procedures make it

difficult for staff to support people with learning disabilities within social care settings. An ethnographic study conducted by Rebecca Hawkins, Marcus Redley and Tony Holland (2011) explored the tension between duty of care and autonomy in specialist residential care homes in the UK for people with the genetically determined condition, Prader-Willi syndrome (PWS). As described earlier in this chapter, this condition can lead to significant overeating, and as a result, serious health problems. This, combined with the mild learning disability people experience alongside this condition means that individuals require specific kinds of care and support to manage their compulsions to eat (Holland & Wong, 1999).

Hawkins, Redley and Holland (2011) observed how, within everyday practice, more of an emphasis was being placed upon managing risk, rather than enabling the autonomy of the people being supported. They also found that although it was possible to formally introduce 'independent activities' (p.879) into daily practice for people considered to be more able, this was more difficult for people considered to be less able. In response to this, 'some support workers deviated from standardised risk management procedures to allow [those less able] service users a degree of independence' (p.873). This involved 'moments comprised of small tasks and were granted in an *ad hoc* manner' (p.880). However, sometimes deviating from organisational rules would go wrong, as is described on one occasion when a support worker permitted a person with PWS to pay for their purchase in a café, and it later transpired that they had purchased a cake without permission. The result of this was that the support worker was reprimanded for their actions. Hawkins, Redley and Holland argue that because of the focus upon risk management, it was difficult for support workers to recognise the autonomy of the people they supported. They suggest that the 'ad hoc' decisions made by support workers to enable residents with independence were indicative of the ways that the tensions between protection and autonomy were not being resolved at the level of organisational, national and international policy.

Elsewhere, a study by Michael Dunn, Isabel Clare and Tony Holland (2010) details findings from in-depth interviews and observations with support workers in a residential care setting providing support to adults with learning disabilities

who lack capacity. In this, the authors explored how support workers made substitute decisions under the Mental Capacity Act 2005 for people they were supporting. In doing so, support workers describe how, to 'make sense of their work', and provide what they believed to be 'good' care, staff drew on 'their own values and life experiences to shape the substitute decisions they [made] on behalf of residents' (p.144). In showing that support workers were drawing on their own personal experiences, rather than what is described in legislation, this study reveals the importance of understanding how policy gets interpreted through context-specific care values in everyday practice. This study involved substitute decision-making on behalf of people who lacked capacity to decide for themselves. To this end, the context here is quite different from the other studies I have described. However, the findings still help to highlight the complex relationship between policy and practice and the need to empirically understand what is happening in the contexts of people's everyday lives.

In exploring the enactment of political empowerment for people with learning disabilities, Marcus Redley and Darin Weinberg (2007) ethnographically explored the self-advocacy group, the Parliament for People with Learning Disabilities (PPLD). The PPLD are a group of 30 people with learning disabilities elected to support managers and commissioners in the service design and management processes of learning disability social care. An advocacy group such as PPLD, Redley and Weinberg acknowledge, 'advances a powerful symbolic claim to conformity with a liberal model that specifies citizenship essentially in terms of active political participation' (Redley & Weinberg, 2007: p.768). In this context of political empowerment, however, Redley and Weinberg ask:

'To what extent can a group of service users, whose very entitlement to state-sponsored assistance is justified by putative intellectual impairment, be empowered according to an exclusively liberal model of citizenship that presumes and requires, as its very defining features, intellectual ability and independence?' (p.767).

Redley and Weinberg's ethnographic study found that, despite the compelling force of the political symbolism of active citizenship, people with learning

disabilities were materially hindered by their impairments in these political contexts. This was, they describe, manifest in the 'interactional difficulties [people with learning disabilities] exhibited in taking and holding the floor' (Redley & Weinberg, 2007: p.782). In this way, Redley and Weinberg illustrate the limits to the liberal model of democracy for people with learning disabilities (p.783).

Importantly, however, they explicitly make the point that they are not challenging the importance of giving voice to the views of people with learning disabilities, and of the importance of celebrating and supporting the development of their abilities, which, in recent decades, have been championed within policy and academic literature (they cite the following documents and authors as examples of this: Goodley, 2000; Department of Health, 2001; Antaki, 2001; Rapley, 2004). What they are challenging, is the tendency to frame the material difficulties people with learning disabilities experience as social constructions. In relation to this, they remark that there is 'a very serious political danger' in taking the social model to the point where people's difficulties in realising their 'voice, ability and independence' are not acknowledged (Redley & Weinberg, 2007: p.768). Redley and Weinberg continue to argue that locating the source of the problem solely in institutions and social relations means that the material needs associated with people's disabilities are not tended to. This then leads to aspects such as 'care', 'security' and 'wellbeing' being superseded by liberal models of citizenship (p.782). As such, they argue, it is important that 'these liberal democratic initiatives must not be allowed to eclipse our recognition that learning disabled citizens need and deserve special assistance in the first place' (p.783).

In positing this argument, Redley and Weinberg align themselves with the existing school of thought discussed earlier in this chapter that has criticised disability social theories for their romanticised views of society and of people with learning disabilities themselves (Burton & Kagan, 2006). Redley and Weinberg argue that part of the problem is that ways of thinking about supporting people with learning disabilities are polarised. On one end of the spectrum there is the current approach, which attempts to empower people by situating them within the liberal model of democracy. This approach is positioned in direct opposition to what are now viewed as institutional and overly paternalistic caring practices at

the other end of the spectrum. In creating these binaries, Redley and Weinberg state, there is little room for manoeuvre between the conditions of liberal democratic political empowerment and that of paternalism. In relation to this, Redley and Weinberg found that, when it became clear that people with learning disabilities were experiencing difficulties in interacting with others as active and politically empowered citizens, there would be a habitual move back towards interactions governed by paternalism. However, they argue that it is not 'inevitable' that this should happen (p.783). They contend that it is possible to create a balance between empowering people with a political voice whilst also providing support and assistance when they need it. However, if this is to be achieved, it will need to involve staff developing skills in the 'detailed analysis of interaction' so that they are able to respond to and advocate on behalf of the people they are supporting (p.783).

In framing these issues within a liberal democratic context of political empowerment, Redley and Weinberg's study draws out the tensions that exist within contemporary social care more generally. In their study, the aspiration towards political empowerment is played out alongside the reality that people with learning disabilities require support in many different areas of their lives. Although the amount of support required by people is variable, the fact that this will impair their ability to assert their active citizenship is inescapable. Crucially, in highlighting this, they show that ignoring the limits that a learning disability can put on people's ability to live their lives in certain ways can mean that aspects of support such as 'care' 'security' and 'wellbeing' are potentially being side-lined (p.767).

### **Chapter conclusion: moving forward**

In this chapter, I have attempted to illustrate the ways in which people with learning disabilities have been constructed through various identities, including citizen, consumer, employer, employee and friend. These identities also sit alongside people with learning disabilities as vulnerable adults, in need of protection. These are a complex amalgamation of differing social, political and economic concepts about how people with learning disabilities might most

successfully achieve fulfilling and meaningful lives within or outside of state support. I have described the range of research that has attempted to understand these varying constructed identities of people with learning disabilities, including how these constructions might be worked on, altered and even transformed to improve people's lives.

In intending to contribute to the ongoing debate in this area, I argue that the lives of people with learning disabilities, including their relations with people who support them, require a methodology with the capacity to capture the situated nature of their complex lives. I want to take Redley and Weinberg's analysis above as a stepping off point to try to develop a fuller understanding of the experiential space between empowerment and protection as it is being played out in people's everyday lives. The fact that each person is different means that this will 'look' differently across people and contexts, and this is where the use of ethnography becomes vital. In using an approach and techniques that capture the world through people's own eyes, at the moment their lives are being lived, ethnography will allow me to observe how policy objectives are being enacted at the domestic level in all their multiplicity. In order to then lift these granular observations and experiences from their local context, I will triangulate them with wider concepts, theories and relational structures. Accordingly, in the next chapter, I further set out the arguments for the value of an ethnographic approach, in terms of why this was appropriate to this study and how it was achieved.

## Chapter three

### Methodology and methods

#### Introduction

This chapter focuses on the empirical stage of the research. Here, I describe and justify my choice of ethnography as an approach. I do this by first defining this methodology and showing how it 'sits' in relation to my theoretical positioning and research question. In doing so, I indicate how this is favourable over other approaches driven by alternative theories. I then describe the places and people who were involved in the ethnography, and how access and informed consent of participants were sought. From here, I move on to the study design itself, including descriptions of the methods used to collect findings, as well as how these findings were analysed. I show how, through detailed participant observation (recorded with extensive field notes), semi-structured interviews and informal conversations, I was able to capture rich, holistic insights into people's social relations and practices. From these insights, I was able to describe and analyse the emerging, subjective and interrelated nature of people's social and material worlds, including the explicit and implicit complexities – patterns, discrepancies and ambiguities – that made up their worlds. Throughout this chapter, where necessary, I also acknowledge the reflexive nature of ethnographic research, including the ways that the approach gives rise to a number of analytical and ethical issues that needed to be considered within the study.

*'But that's the name of the game. You're artificially forcing yourself to be tuned into something that you then pick up as a witness – not as an interviewer, not as a listener, but as a witness to how they react to what gets done to and around them' (Goffman, On Fieldwork, interview, 1989: p.126).*



### **Stepping off from the previous chapter**

In this thesis, my aim is to explore how government policy is interpreted and enacted in UK-based contemporary learning disability support. Broadly speaking government policies are designed around both empowering people with individual autonomy over their lives whilst also recognising a responsibility to protect 'vulnerable' people from harm (Care Act, 2014). In the previous chapter, I reviewed the literature that has assessed the transformations UK governments have made to learning disability social care policy over recent decades, including the complexities and controversies surrounding these policies and the ways they present, at times, conflicting and troubling constructions of people with learning disabilities. In this chapter I describe how I explored these aspects in my own study through ethnography.

### **Justifying an ethnographic approach**

As a methodology, ethnography is adept at capturing the multiple, emergent and complex nature of everyday life (Willis & Trondman, 2000). Furthermore, it also has a reputation for 'unravelling the contradictory, paradoxical aspects of human practice and the subtle workings of power' (Doherty, 2015). The everyday as experienced by people with learning disabilities and support workers could also be described as multiple, emergent and complex in nature. Moreover, as has been indicted in the previous two chapters, for many reasons, social relations in this area of social care support do indeed involve the kinds of contradictory, paradoxical and subtle elements of social life that ethnography can help to uncover.

As a contemporary methodology, 'ethnography itself can be elasticized to encompass fantastically diverse projects and questions' (Chung, 2009: p.71). In this sense, ethnography is difficult to define prescriptively because each study is primarily driven by the people and places themselves (Willis & Trondman, 2000). In this thesis, I used ethnographic approaches and in this chapter I will describe how I interpreted and applied these methods so that they were appropriate to my subject of study.

Ethnography is historically rooted in the discipline of anthropology, and as such, its heritage is situated within studies undertaken on the social lives of 'colonized, deprived and marginalized groups of people' (Doherty, 2015). This disciplinary orientation could similarly be seen to accord with the lives of individuals with learning disabilities, many of whom experience social isolation and feel the impact of inequalities (Simpson and Price, 2009). Perhaps the most crucial aspect of these similarities is that ethnography lends itself to exploring the lives of people who 'are not of the dominant culture, but, instead, participate in a life-style that has certain subcultural features' (Bercovici, 1981: p.139). This is achieved by exploring the world through the eyes of people themselves, which enables their own world views to be expressed – or at least approximated – through the ethnographer's interpretations. Furthermore, it is also the ability of ethnography to capture those situated experiences that make this approach highly suited to the context of support for people with learning disabilities, individuals who can experience difficulty in verbally accounting for their views and experiences. As such, capturing these voices through situated experiences enabled them to be known to me as the ethnographer.

It is through forms of participant observation that ethnography seeks to capture these first-hand experiences of what is going on; to see the world through the eyes of the people under study (Willis & Trondman, 2000). It can also be used in an inductive way, and with this the ethnographer must engage themselves experientially – their body and their mind – in the processes of collecting and analysing what they find (Goffman, 1989). This is opposed to research approaches that use external instruments and/or statistical, mathematical or computational processes to observe and measure. Using participant observation fitted well with my research, which aimed to develop an in-depth understanding of people's life worlds through embodied experience and observation of social action and interaction. Indeed, in their ethnographic study of group homes for people with learning disabilities which I discussed in chapter two on pp.68-69, Clement and Bigby (2010) point out how ethnography was favourable over other quantitatively driven approaches:

‘Participant observation allowed the examination of phenomena that are less accessible to ‘quasi-experimental’ research. The day-to-day contexts of group homes were explored, revealing the specific situations, circumstances and problems facing the people who lived and worked in these settings and the processes by which they responded to them’ (p.35).

Accordingly, in my research both observing and participating over a long period of time allowed me to construct a narrative from participants’ perspectives (Hammersley, 1990). Another aspect of ethnography is that of gaining in-depth and rich insights into people’s lives. In order to achieve this, the numbers of people involved in the study remained small. Spending an intense period of time with a small group of people enabled me to grasp the nuances of how the various constructions of people with learning disabilities, as set out in policy objectives, were being enacted in everyday support.

More than this, however, the approach of ethnography acknowledges that the nature of social relations is myriad and complex. Participant observation, along with other methods, enabled me to capture these relations. These different accounts could then be triangulated, which provided a thickly layered picture of what was being experienced and observed. It is important here to clarify my use of the term triangulation. I am not referring to the interpretation of triangulation which describes the aim of achieving a singular truth through the use of a number of methods collaboratively (Patton, 2002). Instead, my interpretation of triangulation accords with what Hammersley and Atkinson refer to as ‘reflexive triangulation’ (1983, p.200) in that, rather than seeking confirmation that people were doing what they said they were doing, I was interested in exploring the nature of discrepancies between what they said and did. During fieldwork, this was achieved by using the different methods of participant observation and interviewing in an ad hoc manner over long periods of time with a view to ‘thickly’ interpreting the field (Geertz, 1973). For instance, I was able to conduct participant observation with the same people in different contexts over a number of months, which enabled me to build up deeply layered and embedded interpretations of people’s lives.

Further to the above, just because I intended to explore the world through the eyes of the people under study does not mean that I am necessarily giving factual credence to their realities, even if they themselves believe them to be true. Instead, collecting findings using a number of methods, for example observing what people do as well as asking them about this, is a rigorous way of extrapolating a perspective on what is going on (Hammersley & Atkinson, 2007). To this end, ethnography acknowledges that experiences are subjective. The implications of this for my study meant that each person's experience of policy objectives was likely to be different. This has also had implications in terms of what I have been able to say about policy objectives and of how the corresponding constructed identities of people with learning disabilities were interpreted across everyday practice. However, in collecting people's subjective experiences, through reflective triangulation as described above, along with abstract theorising, I sought to move beyond the limits of relativism by situating what was interpreted at the local level within broader social and historical structural forces. This allowed me to develop an understanding of the complex interplay between the particular and the whole (Bates, 1996). In this way, it was possible to think more conceptually about what had been found, which then allowed me to extrapolate more widely from the findings of my study and to situate these findings within wider agency-structure debates.

A central aspect of this within the context of my research was considering the subjective realities of people with learning disabilities, in terms of the fact that their cognitive impairments may have impeded their ability to determine whether they were being empowered. Explorations relating to this may consider whether some people can have power exercised over them even if they are not fully aware of it. This gave rise to questions such as, did people with learning disabilities just say they wanted independence because that is what they believed people around them wanted to hear? Accordingly, what people with learning disabilities said could then be triangulated with how they behaved.

One of the implications of triangulating what people say with what they do is that this enables the ethnographer to get beneath what might be surface level descriptions. This then enables the ethnographer to open up potentially new

interpretations of people's lived experiences. As such, challenging the status quo of embedded assumptions about the lives of people with learning disabilities has been an important element of interpretation in this study. For instance, this has involved consideration of potentially controversial ways of thinking about what is happening in the context of social care, including how policy objectives may be unintentionally placing unrealistic expectations upon people with learning disabilities.

Returning to Clement and Bigby's descriptions of ethnography, in pointing out that this approach is not commonly used to research the lives of people with learning disabilities (Clement & Bigby, 2010: p.35), they set out ethnography's advantages, describing what it can achieve in this context. Here they draw on other researchers' separate findings, and pull these together to indicate the multiple layers of relations in group homes, which an ethnographic approach can capture:

'Ethnography looks to describe and interpret a cultural or social group (Creswell, 1998). This focus on 'culture' begins to fill-in the gap on 'organisational culture' identified by Walsh *et al.* (2007), the 'informal service culture' by Hastings *et al.* (1995) and 'informal workplace culture' by Felce *et al.* (2002)' (p.35).

This stance towards describing and interpreting a multi-layer of cultures chimes with the different constructions of reality that I explore in my research. Similarly to Clement and Bigby above, through ethnography I sought to experience and interpret the multiple subjective realities that exist within support settings. Firstly, I have already looked at how government policy has constructed a range of social, political and economic identities for people with learning disabilities. As I have addressed across chapters one and two, these identities are defined in terms of, at times conflicting, concepts of individual autonomy, (Clarke, 2006) as well as the need to project people with learning disabilities as vulnerable adults (Care Act, 2014). Secondly, through the empirical stage of the research my aim was to explore how people with learning disabilities and support workers made

sense of these identities through their everyday interactions and lived experiences.

### **Theoretical underpinnings: levels of reality**

In relation to the multiple realities I have outlined above, there are theoretical implications of which I must be aware. In taking the ontological view that there are multiple realities, I acknowledge that these are constructed by people as they interact with people and things in the world. Reality in this sense is highly interpretive and, importantly, shaped by our individual and cultural trajectories, for example through culture and language (Holstein & Gubrium, 2000). It is important to point out here that my stance towards reality does not locate subjective and objective realities in binary ways. Rather, it accords with the viewpoint that acknowledges a reality 'out there', but which cannot be accessed outside of human consciousness (Cohen, Manion & Morrison, 2007: p.7). Yet, through qualitative research – experience and observation of human behaviour – it may be possible to get closer to what is actually happening. Given that the ontological stance of this research was concerned with reality that is multiple and emergent, it was fitting that I follow an interpretivist approach (Schwandt, 2000). Accordingly, the epistemology of interpretivism holds that knowledge is not external, objective and singular, but that it can be 'known' through subjective observation and experience of phenomena in the world (Schwandt, 2000). The following extract indicates the ways that we, as humans, are situated in the world:

“We’, human beings, are first and foremost the subjects who do the observing of this world; the collective makers of the photograph of reality ... We are nodes in a network of exchanges ... through which we pass images, tools, information and knowledge. But we are also an integral part of the world which we perceive; we are not external observers. We are situated within it’ (Rovelli, 2015: p.64).

## **Reflexivity**

Importantly, the extract above also illustrates the implications for the way we, as humans, are able to observe the world, not from outside but from within it. Given this, it is also necessary to acknowledge that observed behaviour is open to multiple limitations:

‘The images we construct of the universe live within us, in the spaces of our thoughts. Between these images – between what we can reconstruct and understand with our limited means – and the reality of which we are part, there exist countless filters: our ignorance, the limitations of our senses and of our intelligence. The very same conditions that our nature as subjects, and particular subjects, imposes upon experience’ (Rovelli, 2015: pp.65-66).

As such, in the context of research, the ‘quality’ of research findings must be judged in terms of the rigour in processes of collecting and analysing what is observed and experienced. One of the epistemological challenges to using an interpretivist approach in a rigorous manner is that the researcher’s interpretations can never be entirely free from their subjective values and pre-existing experiences, which emerge, for instance, as embedded, taken-for-granted assumptions (Berger, 2015). Here, I acknowledge ‘the crisis of representation’ (Marcus & Fischer, 1986) and ‘reflexive turn’ (Mascia-Lees, Sharpe & Ballerino Cohen, 1989) within the social sciences, and contend that rather than claiming to be able to dissolve all power imbalances, I instead try to make myself aware of these, drawing them out through the complex processes of analyses, thick description and being open to multiple readings (Luttrell, 2000).

Given that an intention of using an ethnographic approach is to capture multiple subjective realities, acting reflexively to determine between differing assumptions was particularly important in the context of my research. It was a means by which I could compare my subjective reality with those of policy makers, people with learning disabilities, support workers and other staff. This was achieved through iterative and reflexive interpretation and analysis. Throughout the research, I applied the reflexive technique of continually moving back and forth between

differing interpretative constructs that emerged from findings and analyses. Taking this approach was beneficial for both 'iterative-inductive' (O'Reilly, 2005) processes of the research in that stepping 'in and out' of contact with people and places over a long period of time allowed me time and space to think deeply about what I had been experiencing and observing in terms of how it might relate to assumptions and/or wider social phenomena (O'Reilly, 2009). To this end, from the very early stages of fieldwork, I attempted to establish an emerging and iterative relationship between the research questions, the findings, and the theory and interpretation (Talmy, 2010). In order to conduct more in-depth processes of analysis, at various intervals I also took extended breaks from the field for up to two weeks.

### **Starting out in the field**

Having set out my argument for the chosen methodology, as well as how this 'fits' with the theoretical assumptions and research question, I now provide information relating to the more practical aspects of the research. Fieldwork was conducted for just over nine months, from the beginning of July 2014 until the beginning of April 2015. The start date here refers to the beginning of the fieldwork proper. However, there was a 'lead in' period from January 2014 when contact was made and meetings conducted with managers of each service to seek their participation (see Appendix 1, Figure A for a detailed timeline of the doctorate and Appendix 1, Table A for a full break down of number of visits per month and hours accumulated in the field).

The majority of the fieldwork was conducted across two learning disability provider organisations, which I have called Singertree Trust and Cambrick, both based in the South-West of England. I also spent time in two independent organisations, an advocacy service, who I have called Hear Us and a church café, which I have called Station Park Café. Contact with these independent organisations had not been planned at the start of the research, but instead occurred naturally as deeper immersion in the field developed. In various ways, these independent organisations were also involved in supporting people with learning disabilities in and around the areas in which my fieldwork was based.



For anonymity purposes, all names of places and people included in this thesis have been changed (see Table 4.1 on p.115 in chapter four for full list of organisations/services in which I spent time).

### **Fieldwork setting selection**

From January 2014, I began with a brief internet investigation, focusing on learning disability provider services in the area of England where I was situated. As I was seeking to explore how policy is enacted in everyday practice, it was necessary that the selected organisations were adhering to UK government policies. It was also necessary that their services were set out in ways that would allow me to observe and experience practices taking place, and talk to people about this. In a pragmatic sense, it was necessary that the organisations themselves agreed to take part, and so after narrowing down my search to two organisations that fitted my requirements, I made initial telephone contact with senior managers: Sarah Hill at Singertree Trust and Julie Davies at Cambrick (for anonymity purposes, all names of people included in this thesis have been assigned pseudonyms). During these conversations, I briefly described my proposed research and interest in becoming involved with their organisations. I then took the opportunity to request face-to-face meetings – which both agreed to – with a view to speaking in further detail about what I was hoping to do. At this early stage, I was keen to introduce myself to both Sarah Hill and Julie Davies in order that I could begin the processes of relation building.

At the time of writing this thesis, the two organisations, Singertree Trust and Cambrick, were both independent non-profit distributing organisations providing publicly funded health and social care adult services to individuals over the age of 18. They both fell under the category of social care provider services, meaning that they were commissioned through their respective local authorities. Singertree Trust delivered services nationwide, provided solely to individuals with learning disabilities. Cambrick provided health and care and support services within a single part of the country to individuals with learning disabilities, as well as other adult groups. Each organisation provided housing services – including

supported living, residential and nursing care – and day support services – including employment training, therapeutic services and day centre services.

### **Situating myself in the field**

After the face-to-face meetings, both Sarah Hill from Singertree Trust and Julie Davies from Cambrick agreed to take part. From here, between January-July 2014 a subsequent number of introductory conversations and/or meetings took place with each organisation. Permission to spend time with the independent organisations, Hear Us and Station Park Café, was not sought at these early stages of the study design because contact with these organisations had not been planned at the start of the research, but instead occurred naturally as deeper immersion in the field developed.

During the early stages of meeting both Sarah and Julie, it became apparent that a condition of my being provided access to their services would be that, where needed, I would “help-out” or act as an “extra pair of hands”. Indeed, this condition is included in the formal letter of agreement from Cambrick (see Appendix 2, for copies of acceptance letters from the two provider organisations). During the fieldwork, I spent time in day centres, people’s homes and at employment training services (details of these are described in more detail in chapter four). In accordance with the wishes of both Singertree Trust and Cambrick, whilst spending time at people’s homes, I would help-out with daily chores and other activities, such as filling the dishwasher, ironing, preparing meals and cups of tea and coffee. Whereas in other places, such as employment placements, I would attempt to relieve the workload of support workers by assisting them in supporting people with learning disabilities with their daily activities.

In a practical sense, taking on this dual role of ethnographer and informal supporter was helpful in terms of enabling me to ‘slot’ into the different environments and becoming a part of the social and material fabric of daily life. This is a recognised ethnographic strategy for establishing a rapport with people and maintaining the naturalness of the setting (Seymour, 2000). As well as this however, ‘helping-out’ with care and support was also a benefit methodologically.

Taking a dual role as both an ethnographer as well as an informal supporter allowed me to grasp from a first-hand view point each position. Admittedly, however, there were also challenges to this dual occupancy and, for the purposes of interpretation, at times throughout the research it was necessary that I actively took steps back from each of these roles and reflexively assessed my positionality.

These issues relating to my positionality also bring with them an ethical dimension concerning the necessity to ensure that my positionality was made explicit throughout the research study. Given that I was working with people with learning disabilities, issues relating to the ethics of positionality and how these were ironed out required careful attention. Before fieldwork commenced, I did consider taking on a formal role as a support worker. Initially this was appealing, mainly because it would allow me to enter the field with a pre-defined status, potentially reducing the possibility of being excluded or distanced from certain interactions and practices. However, after seeking advice from my supervisors and other academics with experience of working ethnographically in social care settings, I decided that taking on a support worker role could potentially generate ethical complications – even if informed consent had been granted by participants, my dual role as support worker and ethnographer may have altered my positionality in a way that might have made my role as an ethnographer opaque. This is discussed further in the sections below on processes of consent.

Given that I wanted depth and duration through the study, the numbers of participants needed to be practical to enable this. Moreover, given that I was interested in exploring people's subjective realities, which I have already described as highly interpretive and shaped by individual trajectories, I sought to achieve levels of depth and nuance that would then enable me to interpret what I had observed and experienced and develop interpretations that may have resonance in other settings. It is also worth pointing out that, given the theoretical stance, the study could have been achieved with a single service provider organisation. However, for contingency reasons – in the event that one organisation withdrew their participation – I felt it prudent to seek participation from two organisations.

In the early stages of developing the study design, I anticipated that I would distribute my time equally across Singertree Trust and Cambrick. It transpired, however, that I spent the vast majority of the nine months of fieldwork with Singertree Trust. This was mainly because I was permitted access to only one person with learning disabilities at Cambrick (I explain why this was the case in further detail on p.94), whereas I was provided with access to several people at Singertree Trust. I felt that spending time with different people in varied contexts would be beneficial for the study's analytical breadth as it would allow me to develop insight into different lived experiences. Furthermore, the process of seeking informed consent and organising visits with the one participant at Cambrick took longer than expected, and by the time I started fieldwork at Cambrick, I had already begun developing good relations with people at Singertree Trust, which I did not want to jeopardise by spending less time with them. Although I still gained insight into the lived experiences of the individual at Cambrick, and the people supporting them, the vast majority of my analysis in this thesis was formed from fieldwork undertaken at Singertree Trust. Despite this, however, I decided to continue the weekly visits with the individual at Cambrick. This was largely in recognition of the efforts that managers, support staff and the person with learning disabilities themselves had made to accommodate my research, which made it feel inappropriate to withdraw my request once it had been accepted. Furthermore, given the premise of my research involved exploring the lives of socially isolated groups, cutting off contact did not feel appropriate in this context.

### **Ethical approval**

Since my research was to involve people who use services, the NHS Health Research Authority (HRA) instructed that the study required ethical review by the Social Care Research Ethics Committee (REC), part of the National Research Ethics Service (NRES), which is governed by the HRA. In June 2014, a favourable opinion for the study protocol was received from the Social Care Research Ethics Committee (protocol number: 14/IEC08/0019). Immediately following this, I submitted an application to my university departmental REC, the Research Ethics Approval Committee for Health (REACH), Department for

Health, University of Bath. A favourable opinion was also received from the REACH committee in early July 2014 (see Appendix 4 for correspondence detailing favourable opinions from RECs).

In conjunction with gaining favourable opinions from the RECs above, it was also necessary that I consider any ethical and/or legal requirements made by both Singertree Trust and Cambrick. Accordingly, before the fieldwork proper could commence, I was required to obtain clearance from the Disclosure and Barring Service (DBS). This was obtained on 24<sup>th</sup> March 2014. (see Appendix 4 for copy of DBS Enhanced Certificate).

### **Processes of consent**

Seeking and obtaining consent is a fundamental requirement of ethical and responsible research practice. In accordance with the requirement for consent to be informed, I outlined the research to potential participants, as well as how consent would be formally obtained and recorded prior to their physical involvement. When approaching potential participants and seeking their involvement, I provided people with Participant Information Sheets (PIS), which contained written details about the proposed study and what would happen following involvement. Content of the PIS documents differed between support staff and people with learning disabilities, and people with learning disabilities were offered easy read versions of their document (see Appendix 3 for copies of all PIS documents).

When providing potential participants with a PIS, I explained that they would be given up to two weeks to decide whether they would like to take part. I also explained that, if they agreed to take part, I would invite them to provide formal consent which would be recorded on a consent form. Content of the consent forms differed between support staff and people with learning disabilities, and people with learning disabilities were offered easy read versions of their document (see Appendix 3 for copies of all consent forms). Both support staff and people with learning disabilities were asked to provide formal consent through a written signature. However, where necessary, people with learning

disabilities were given the option of providing verbal consent, which could be then validated in writing by a family member or member of staff who was familiar with the person, and so able to legitimately authorise whether their consent had been given. There are pros and cons in the use of proxy consent. On one hand, it enables individuals who cannot consent for themselves, and who would benefit from involvement in the research, to take part. On the other hand, however, it is not possible to determine with certainty whether an individual has fully consented to take part (Wrigley, 2006). In the event that proxy consent was required in this study, my aim was to attempt to mitigate this risk of someone's decision being misinterpreted (deliberately or by mistake), by ensuring that proxy decision-makers were familiar with the person in question. Furthermore, I also engaged other practices of ensuring consent on an ongoing basis, which I describe in more detail below.

Every person, except two – one person with a learning disability and one support worker – informally agreed to take part immediately upon being asked. The other two participants agreed to take part within the two-week decision period. Although all potential participants with a learning disability were deemed to have capacity to independently decide whether they wished to take part, I anticipated that it was likely that at least some individuals may have required support from others when taking their decisions, and so I decided that it would be prudent to wait for the entire two weeks before asking these potential participants to provide formal consent.

In addition to seeking informed consent from all participants, throughout the course of the research, I employed techniques of retrospective consent (Fluehr-Lobban, 1994) and sequential or process consent (Seymour, 2001; Department of Health, 2009b). These techniques were approved by both Research Ethics Committees (REC) that reviewed my study, on the condition that informed consent be obtained from each participant prior to their involvement in the research. I adopted these additional techniques to ensure, as much as was possible, that people remained aware of what I was doing and what I was asking of them. Together, these techniques acknowledge that, in the processes of qualitative – especially ethnographic – research, situations that cannot be

predicted are certain to occur, and so processes must be put in place to manage this unpredictability to ensure that participants are still consenting. Within my study, ensuring the ongoing consent of participants was particularly pertinent given that people with learning disabilities, individuals who can be particularly vulnerable, were involved in the research.

Retrospective consent can be used by the ethnographer to request consent to include information not covered in the original consent agreement, and allows the ethnographer to request consent from people after an event or situation has occurred. Due to both the emergent nature of ethnography, and context of my research, it was apparent that it would be impossible to predict how events would unfold and, to a certain extent, which people would be involved over the course of the fieldwork. In particular, it would be difficult to seek consent from all the many different stakeholders who were likely to be entering the settings during the extended amount of time I would be spending within them. To this end, in order that individuals entering these settings who had not yet provided consent could be given the option of being involved in the research, provisions were made to allow for retrospective consent to be requested in these circumstances.

The other technique, sequential or process consent, is similarly employed by the ethnographer to request consent to include information not covered in the original consent agreement. Yet, this differs from retrospective consent in that it is the act of obtaining consent whilst the research is taking place, in real time. When deemed necessary, the ethnographer refers to their research and themselves as a researcher to ensure that their primary role remains explicit to all participants. Again, this is considered to be helpful for an ethnographic methodology where it is not possible to know in advance how relationships with and between participants are to develop. Moreover, as ethnography calls for close interaction between ethnographer and participants, there is an on-going possibility that boundaries between them may become blurred. Although such blurring of boundaries cannot be avoided entirely, sequential or process consent is a recognised technique which enables the ethnographer, as much as is possible, to avoid potential situations where information is disclosed or relationships developed under misconstrued circumstances.

Thinking about and being aware of the techniques of retrospective and sequential or process consent were helpful both before the fieldwork started and after it had commenced. For instance, at the start I considered there was a risk that participants may have come to view me as a confidant rather than an ethnographer, meaning that they were potentially vulnerable to disclosing information to someone they considered to be a friend, not considering that this information may be used for the purposes of the research. I was also concerned that some individuals with learning disabilities may find it confusing that I would be spending time with them. Although the issue here was less about concerns with regard to disclosing information that might otherwise be withheld and more about the concern that people with learning disabilities may misinterpret my relationship with them as a personal one, potentially causing them to become overly attached during the process of the research. Although these potentialities could not be avoided entirely, taking the above steps supported the ethical integrity of the research.

### **Storing personal information: anonymity and confidentiality procedures**

In accordance with the Data Protection Act, and good research practice, I developed strategies for protecting people's rights to anonymity and confidentiality. My field note diary, which was written by hand, was scanned and is held on a password-protected University server space. The original diary is kept separately in a locked filing cabinet. The names and places in all other written materials were made anonymous by being assigned pseudonyms. They are kept confidentially on a separate password-protected University server space. Any other written materials with codes pertaining to names and places are also stored on a separate password-protected University server space. Only I have access to these. In line with what is considered to be good research practice, copies of any machine-readable data created during this doctoral research will be offered for deposit at the UK Data Service (ESRC, 2017).

The approach I took to analysing interviews conducted as part of this study, although analytically favourable, did give rise to issues relating to confidentiality



and anonymity, which need to be outlined here. I did not fully transcribe all interview recordings. Instead, to retain the context of interviews, I chose to conduct analysis from the audio recordings themselves. My reasons for doing this are described in further detail in the analysis section of this chapter from p.109. To mitigate these issues, the interviews, which had already been recorded on an encrypted audio recorder, were then transferred to an encrypted flash drive on a password-protected personal computer, after which the recordings on the audio recorder were deleted. Only I have access to the audio recordings. Furthermore, I only listened to the recordings in private places and when using headphones. I used the pseudonyms I had allocated to people and places when taking notes from the recordings.

### **Selecting people to be involved in the research**

Both Sarah Hill from Singertree Trust and Julie Davies from Cambrick had separately expressed that they were keen for me to spend time with people who they felt were complicated cases, but with whom the respective organisations had succeeded, sometimes against the odds, in providing a good range of support. For instance, within Singertree Trust, I sensed that Sarah Hill wanted to make a statement about what she saw as the ill judgments made by their local authority regarding funding and support of some of the people they had selected for me to spend time with - some of whom they felt were being underfunded (I have described details of social care funding, such as needs assessments, on p.22, and this is described in further detail across the empirical chapters). Indeed, this is reflected in the situation of the participants that I was introduced to at Singertree Trust, who are described in further detail below.

In this sense, it is necessary to acknowledge that the selection of participants would be impacted by what both Singertree Trust and Cambrick considered to be success cases and what they deemed good support to look like. This issue is one of the reasons that participants tend not to be selected on behalf of ethnographers (O'Reilly, 2012). For, although it is usually necessary to pre-select the broad social group(s) who will be the subject of study, to avoid pre-determined influences, specific individual participation tends to be attempted in naturalistic

ways, as the ethnographer begins to develop relationships in the field. However, as I have described at the beginning of this chapter, one of the characteristics of ethnography is that it is shaped by the context to which it is being applied. Given that the context of my research involved individuals with learning disabilities who were in receipt of social care support, a population considered to be vulnerable, it was unavoidable that the managers of each organisation providing them support would play a significant role in my access to people.

Having recognised the way that the selection of participants was impacted, I took steps to ensure awareness of this. When collecting and analysing findings, I paid particular attention to the ways that success stories and good care were seen to be taking place, and how these were interpreted through frames of subjective reality in everyday practice. Furthermore, despite these initial constraints in terms of participant selection, once I entered into the field and as I spent time with people in services outside of their homes, I was immediately exposed to other people with learning disabilities and their support staff, which allowed me to capture a broader sense of how support was working.

### **How many people were enough?**

The long term and unfolding nature of ethnographic research means that, over the course of fieldwork, the ethnographer can encounter large numbers of individuals. In addition, the importance placed on conceptual aspects, rather than how frequently things occur or are spoken, means that determining between those who are 'core' participants and those who are 'peripheral' participants was not necessarily straightforward (Emerson, Fretz & Shaw, 2001). Given this, although I considered the participants I spent long periods of time with as core participants, some of the peripheral participants with whom I spent relatively short periods of time were highly significant sources of conceptual knowledge.

When discussing with Sarah Hill at Singertree Trust and Julie Davies at Cambrick the numbers of people I would like to spend time with, I outlined that in accordance with an ethnographic approach, described earlier in this chapter from p.76, one of my aims was to develop in-depth and thickly layered knowledge of

how support was being provided and received. This meant spending time with the same individuals over the course of the whole fieldwork. Accordingly, each organisation selected numbers based on this criterion.

In total, there were 68 participants involved in the study. These consisted of 20 people with learning disabilities (including one individual who was the spouse of a woman with learning disabilities in receipt of services), 47 support workers/other staff members (including two independent freelance advisors), and one parent of a person with a learning disability (I did attempt to include more parents/families of people with learning disabilities. However, many of the older people were not in regular contact with their families, and of the three families I was able to contact, only one individual responded).

Of all these participants, there was a total of 30 core participants (see Table 3.1, p.96) and 38 peripheral participants (see Table 4.2, pp.116-117 in chapter four for full lists of participants and their core and peripheral statuses). Some of the core and peripheral participants are mentioned in the empirical chapters and some are not. Yet, in varying implicit and explicit ways, all the people involved contributed to the research findings. There were also people who I encountered, but never actually met or spoke to, for instance, when I visited day centres. Although there are no explicit references to these individuals, again, they would have implicitly come to shape my interpretations and final conclusions.

At Singertree Trust, the vast majority of my time was spent with eight core participants with learning disabilities and 16 core participants who were support staff. Whereas at Cambrick, I spent time with only one core participant with a learning disability who was supported by three support staff who were peripheral participants. As I have mentioned above, Cambrick only provided access to one person with a learning disability. This decision was made by Julie Davies, who said that she wanted me to develop an understanding of the complexity of people's lives and of the time-consuming nature of the support they received. She felt that this could only be achieved by spending time with one person at a time. Given that in order to arrange access to each of these organisations I was

required to spend a considerable amount of time in contact with the managers based at each, I have included them as core participants.

It is worth pointing to the fact that there is a much larger number of people listed as participants than there are mentioned in the empirical chapters of this thesis. The decision to present the ethnographic material in this way is twofold: firstly, the small numbers represent how the complex nature of social relations in learning disability social care settings required spending long periods of time with a limited number of people to capture these complexities. In turn, presenting in-depth and thickly layered interpretations that sufficiently describe these complex relations required in-depth descriptions and analysis across different contexts in the written material. Secondly, the set-up of contemporary social care residential settings, which are made up of small-scale group homes, including residential care and supported living, also impacted on how many people I spent time with on a regular basis. As I devoted much of my fieldwork time to visiting two houses – Sanderstead View and Chatsview Road, which I introduce on p.98 – the very in-depth findings that emerged from the participant observation came from the small numbers of people living in these properties.

Importantly, however, the accounts I have presented were carefully selected on the basis that they could be made transferable to other experiences that I had observed throughout the fieldwork. The individuals in the empirical chapters therefore are presented as part of ethnographic vignettes or portraits which represent both people's individual lives and illustrate broader issues relating to the lived experience of learning disability social care support.

**Table 3.1.** List of core participants, the organisation they belong to, their status and role.

#	Pseudonym	Organisation	Location	Status	Role
1	Patrick Junes	Cambrick	Hilltop Mews day centre	learning disability	day centre attendee
2	Fred Davies	Singertree Trust	Chatsview Road	learning disability	lived at property
3	Kevin Patterson	Singertree Trust	Chatsview Road	learning disability	lived at property
4	Pamela Jones	Singertree Trust	Chatsview Road	learning disability	lived at property
5	Rebecca Smith	Singertree Trust	Chatsview Road	learning disability	lived at property
6	Ray Winder	Singertree Trust	Chatsview Road / Goatsgruff Farm	learning disability	lived at property, worked at farm
7	Sam Treadwell	Singertree Trust	Sanderstead View	learning disability	lived at property
8	Joey Tammer	Singertree Trust	Sanderstead View / Pigtree Farm	learning disability	lived at property, worked at farm
9	Mark Whyatt	Singertree Trust	Sanderstead View / Pigtree Farm	learning disability	lived at property, worked at farm
10	Julie Davies	Cambrick	Hilltop Mews day centre	staff	day centre manager
11	Fred Peck	Cambrick	Hilltop Mews day centre	staff	locality manager
12	Jo Parry	Hear Us	Head office / Hear Us / I.T.C. events	staff	owner/manager, lead advocate
13	Sheila Biggins	Hear Us	Hear Us / I.T.C. events	staff	advocate
14	Rachael Patrick	Singertree Trust	Chatsview Road	staff	house manager
15	Amanda Wells	Singertree Trust	Chatsview Road	staff	support worker
16	John Robbins	Singertree Trust	Chatsview Road	staff	support worker
17	Linda Watson	Singertree Trust	Chatsview Road	staff	support worker
18	Lucy Lartey	Singertree Trust	Chatsview Road	staff	support worker
19	Sandra Lang	Singertree Trust	Chatsview Road	staff	support worker
20	Shaun Range	Singertree Trust	Chatsview Road	staff	support worker
21	Trish Larks	Singertree Trust	Chatsview Road	staff	support worker
22	Nigel Sutton	Singertree Trust	Head office, Viewpark Centre	staff	locality manager
23	Sarah Hill	Singertree Trust	Head office, Viewpark Centre	staff	operations manager
24	Jane Davies	Singertree Trust	Pigtree Farm	staff	support worker
25	Samantha Hake	Singertree Trust	Pigtree Farm	staff	support worker
26	James Walter	Singertree Trust	Sanderstead View	staff	house manager
27	David Smith	Singertree Trust	Sanderstead View	staff	support worker
28	Emily Gillies	Singertree Trust	Sanderstead View	staff	support worker
29	Doris Armstrong	Singertree Trust	Sanderstead View / Chatsview Road	staff	support worker
30	Steve Connors	Station Park Café	Station Park Café	staff	manager, outreach/community development worker

### **Levels of disability**

Though acknowledged to be a crudely defined set of categories, severity of learning disability tends to be determined between mild, moderate and severely intellectually disabled (Emerson & Hatton, 2008). However, when discussing the core participant selection with both Sarah Hill at Singertree Trust and Julie Davies at Cambrick, I chose not to stipulate to either manager a preference to work with people with a particular level of disability. The reason for this is that these categories are based on assessments that measure people's ability in aspects such as cognition and executive functioning (Emerson & Hatton, 2008). Although knowledge of these measurements can be beneficial in various aspects of care and treatment for people with learning disabilities, they become less relevant in the context of ethnographic enquiry, which is concerned with subjective realities and social relations at a particular time and place.

An argument could be made here that the ability to observe the ways people interpreted policy objectives could be increased by limiting the sample to include people with milder levels of learning disability. This is based on the assumption that this group would be more able to assume the kinds of rights and responsibilities that accompany aspects of these policies, such as independence. However, I am interested in considering these notions of, for example, empowerment in relation to subjective realities, which means that I am also interested in how people are constructed by others and how they respond to these constructions. It may be the case that people with severe learning disabilities may be less able – for instance, in terms of verbal ability – than their mildly disabled counterparts to respond to the ways they are constructed within these settings. Yet, there may well be other observable ways that they are doing this, which can be captured through an ethnographic approach exploring subjectivities.

### **The field sites**

Given that the primary participants with learning disabilities and their support staff were at the centre of my doctoral research, the homes and places they lived, visited and worked in dictated the primary research sites. There were three

primary field sites – places where the majority of research took place – Chatsview Road, a residential care home, Sanderstead View, a supported living home, which were both part of Singertree Trust. In addition, I spent time at Hilltop Mews, a day centre belonging to Cambrick. Sarah Hill at Singertree Trust and Julie Davies at Cambrick selected the sites on my behalf after I had described to them the types of people and services I was interested in finding out about in relation to my research question of exploring how government policy is played out in everyday learning disability support. After Sarah and Julie had informed me about their selections, I used the People with Learning Disabilities in England 2013 census report (Public Health England, 2014) to assess whether the services I had been provided access to corresponded to services broadly representative for social care in England. I deemed the suggestions given by Sarah and Julie to be appropriate and so agreed to go ahead with these.

Earlier in this chapter on p.83 I described that, in addition to working with Singertree Trust and Cambrick throughout my fieldwork, I also made contact with other independent local organisations who were in various ways involved in supporting adults with learning disabilities in the community. Contact was made with these individuals and groups through snowballing techniques (Vogt, 1999). These included a local advocacy group called Hear Us, run by Jo Parry, and a local church project, Station Park Café, managed by Steve Connors, which employed people with learning disabilities in paid work and in volunteering capacities. The initial intention behind accessing these other groups in addition to Singertree Trust and Cambrick was to broaden my experience and interpretation of community services for people with learning disabilities. It was also to develop an idea of what kinds of other non-statutory services existed for people with learning disabilities. Further still, I was interested in finding out how the statutory and non-statutory services sat alongside each other in ‘the community’ and the part each played in the lives of the people they supported and worked with.

It transpired that many of the people with whom I was making contact through Singertree Trust and Cambrick were also accessing these non-statutory services at Hear Us and Station Park Café. In terms of my research project this was very

helpful as it allowed me to spend time with the same people in multiple contexts, becoming a part of their social networks. Whilst conducting fieldwork, I felt that the close contact the different services had with one another created a sense of cohesiveness. However, on reflection this could possibly also be interpreted as indicative of a limited amount of services in these areas.

### **Becoming a participant observer**

During the just over nine-months of fieldwork, I spent three to five days per week in the field, with days generally lasting between six to eight hours. It could be argued that spending longer periods would have been advisable, to ensure that full immersion and 'saturation' was reached (Iphofen, 2013: p.10). However, during this time, I was taking on the dual role of informal supporter and ethnographer, in which I was required to interact and observe with two distinct groups of people with learning disabilities and the individuals involved in supporting them. Although all ethnographic research is demanding on the ethnographer, within this particular context, I found time in the field to be especially physically and emotionally draining. This was in part due, I feel, to the often-intense nature of working with people with learning disabilities, which can require the people spending time with and/or supporting them to assume several roles, including for example, carer, friend and personal assistant. Furthermore, to ensure personalised services are being provided, a common feature of contemporary social care support is that people are supported either on a one-to-one basis or in small groups. Although this is beneficial for people in receipt of support, it arguably expects a great deal from the individuals providing said support. During my time in the field, in some ways I felt exposed to these challenges as I spent considerable amounts of time with people with learning disabilities either on a one-to-one basis or with small groups of people.



## **Ethnographic methods**

### **Participant observation**

As I described in the opening sections of this chapter, despite its elasticity in terms of applicability and approach, all ethnography seeks to capture first-hand experiences of what is going on – to both observe what people do as well as to attempt to see the world through their eyes (Willis & Trondman, 2000). For this reason, the method of participant observation tends to be an essential part of ethnography (Atkinson & Hammersley, 1994). In this approach, however, there are implications for the ethnographer, in terms of what they must do in the field. What this entails is nicely elucidated in the following lines by Erving Goffman in which he describes the implications of this process for the ethnographer:

‘By participant observation, I mean a technique that wouldn’t be the only technique a study would employ, it wouldn’t be a technique that would be useful for any study, but it’s one of getting data, it seems to me, by subjecting yourself, your own body, and your own personality, and your own social situation, to the set of contingencies that can play upon a set of individuals, so that you can physically and ecologically penetrate their circle of response to their social situation ... so you are close to them while they are responding to what life does to them’ (Goffman, 1989: p.125).

In this statement, Goffman uses the technique of participant observation to illustrate some of the key methodological aspects of ethnographic enquiry, which I introduced at the beginning of this chapter from p.76. Through this he shows how ethnographic techniques – or methods – capture knowledge of the world in ways that require the ethnographer to literally ‘put’ themselves in the way of others’ lives, with both their ‘body’ and their ‘personality’. In using their own embodied experience as an instrument for capturing findings the aim is to get beneath surface-level descriptions and taken-for-granted assumptions of the world, with the hope of coming to a deep understanding of how people respond to ‘what life does to them’. In this sense, the methods are not solely techniques

to be employed instrumentally, rather they are extended articulations of the epistemological shape of this methodology.

Being immersed in the research setting in this way and over a long period enables the ethnographer to be privy to a myriad of interactions between people, including those that might not be captured through interview alone. The way that participant observation can provide the ethnographer with access to a range of complex and nuanced expressions and communicative practices is beneficial for gaining insight into all lived experiences. However, it took on a special significance in terms of how I was able to observe and engage with people with learning disabilities. There is much evidence to show that many people with learning disabilities can deeply reflect on their lives, as well as express their wishes in meaningful ways (Walmsley & Johnson, 2003; Johnson, 2009). Indeed, during my fieldwork, I often experienced first-hand people's ability to do this. Yet, as I also described at the beginning of the chapter on p.77, there is evidence to show that many people with learning disabilities do, to varying degrees, experience difficulty in verbally conveying their lived experiences, especially ones that are emotionally complex (Jahoda, Wilson, Stalker & Cairney, 2010). To this end, participant observation, which does not solely rely on people verbally accounting for themselves, was a vital means by which to capture life as it was really happening and in all its complexities for people with learning disabilities.

These issues of capturing those subtle aspects of lived experiences which are ordinarily hidden from view speaks to the importance of the role of the ethnographer as both insider and outsider (Herbert, 2000). Although it is the role of the ethnographer to experience people's lived realities as much as possible, it is also their role to step in and step out of these realities. Such an approach was particularly beneficial in the context of this research, given its complex nature in terms of the multiple and subjective realities at play.

Throughout the fieldwork, I engaged in participant observation at all stages. After every visit, I recorded my experiences and observations in field notes, which I then coded and analysed, the processes of which are described in more detail in the sections below. I used these findings to inform the direction of the semi-

structured interviews. The interview findings were then triangulated with the information collected during participant observations with a view to building up thicker layers of interpretation. I describe my approach to analysis of field notes in more detail below.

### **Field notes**

I recorded my observations through extensive field notes (Morse & Field, 1995). The act of writing ethnographic texts is not solely for the purposes of documenting what has been experienced and observed, but is also part of the analytical enquiry itself (Coffey & Atkinson, 1996). Given that field note writing is a crucial part of the processes of recording and analysing there were a number of rules I followed when constructing them. Though the field notes would never be entirely accurate recordings of what I experienced and observed, I was aware that it was important that they should be written up as soon as possible after leaving the field, to capture things in as much detail as possible. However, I was keen that this would not disrupt the natural flow of social relations and practices in the field, and so I made all notes after leaving the field (there were only a few occasions when I made notes when in the field sites. These were occasions – such as when I was sitting in on meetings – when having a note pad in front of me and writing would not have disrupted the natural flow). I travelled to most fieldwork sites by train or bus, which was helpful as my return journeys were usually spent writing the field notes from that visit. Finally, to build up thickly layered accounts of my experiences and observations, I wrote field notes after every visit to the field, which were titled with location, time and date of the visit.

The shape of field note writing accorded with the theoretical underpinnings of ethnography, which view knowledge as emergent rather than ‘out there’. This was reflected in the development of field notes from descriptive to conceptual. When first commencing with field note writing at the beginning of the research, entries were highly descriptive. Although from the outset I began recording my own feelings and reflections of what I was seeing and experiencing, these early field notes were mostly made up of introductory descriptions of the material fabric of the settings and the people with whom I was meeting for the first time:

‘Arrived at the centre just before 8.30 a.m. today, and Frank, one of the support workers, arrived just after me so I followed him into the building. There weren’t any people with learning disabilities there yet, so we had a bit of a chat. Frank asked me about my project. He then started describing what the centre at Bristlehedge is about – he said that they were providing work opportunities for people with learning disabilities. They tried to create as realistic a working environment as possible’ (field notes, 25<sup>th</sup> July 2014).

After becoming more familiar with places and people, these descriptive accounts began to be layered with observations and experiences of social interactions and practices. I would particularly focus on those interactions and practices where policy objectives appeared to be playing out. After deep immersion in the field was achieved, field notes eventually became made up of very little descriptive content, just enough to paint a picture of the settings in which I was in. Instead, I began to use field note writing to explore developing and unfolding conceptual themes that were being experienced and observed in the field:

‘I was speaking with Shaun today [a support worker], and he was explaining that he had started working here [Chatsview Road] because he had injured his back and so needed to be moved to somewhere that did not require lifting. This conversation reminded me of when I had been supporting Ray [a person with learning disabilities living at Chatsview Road] to get up from his bedroom chair, and Rachael [the house manager] walked in and told me in front of Ray that we weren’t allowed to lift people. The removing of work such as lifting people establishes a reality whereby support workers are absolved and/or absolve themselves of certain responsibilities towards the people they support. The removal of these responsibilities impacts upon the relationship between them ... the ability of staff to relate to people they support in the way that they might with other humans is perhaps diminished’ (field notes, 21<sup>st</sup> January 2015).

### **Formal interviews and informal conversations**

Here, I define formal interviews as pre-arranged and recorded meetings when I used an encrypted audio recorder or took notes manually (O'Reilly, 2012), and informal conversations as those that took place during the natural flow of interactions during fieldwork, which were later recorded in field notes (O'Reilly, 2012). In neither of these methods did I approach people with written questions. However, I did come with semi-structured ideas and themes that I intended to explore (Silverman, 2007), which I had either come to the field with, or which had emerged from the participant observation (see Appendix 5, Figure A for details of broad interview/discussion themes).

I engaged in informal conversations with individuals who regularly featured in the participant observation. As I was spending long periods of time with these individuals, it felt appropriate to integrate this method into interactions in a naturalistic way. By interweaving this approach into the participant observation, I engaged in informal conversations at all stages of the fieldwork.

In chapter two on p.60, I described how the cognitive impairments experienced by people with learning disabilities present problems for researchers in terms of actively including them in research processes. For example, the use of interviewing as a means of capturing people's views and perspectives is methodologically challenging with people with limited language proficiency, and who also tend to experience social anxiety, all of which can mean people are unresponsive to open questioning. Furthermore, people with learning disabilities can also experience difficulty in generalising and thinking conceptually about their experiences and views, abilities which are key to capturing material through the method of interview. (Booth & Booth, 1996). There are techniques that researchers use to overcome these challenges. For example, avoiding generalised and conceptual thinking and using direct questioning (Booth & Booth, 1996). Elsewhere, specific tools such as Cue Cards (Lewis, Newton & Vials, 2008) and Talking Mats (Murphy & Cameron, 2008) have been used to provide both structure and open interaction to support people with learning disabilities to overcome the barriers they experience in expressing themselves.

However, I agree with Goodley (1998) in his stance that with such heterogeneous groups as people with learning disabilities, there can be no set standard for interviews and that it is down to the researcher to consider how to best approach and interact with the person in the context. In my ethnographic study, this more fluid approach worked well as I could incorporate open-ended questioning, in the form of informal conversations, within the social fabric of everyday life for people with learning disabilities. This allowed my questions to feel more natural and less out-of-place than formal interviewing might have, which could have been intimidating and cognitively challenging for people with learning disabilities.

When conducting formal interviews, in order to create some common ground from the start, I would begin with describing incidences that had occurred with people who I knew the interviewee was familiar with. I found that this tended to allow the interview to get into a natural flow and for the interviewee to feel relaxed. From here, I then attempted to interweave into the experiences we were discussing relevant themes and ideas that had emerged and been developed through my observation and analysis. For instance, when discussing how one participant with learning disabilities, Mark Whyatt, had an interest in watching and purchasing wrestling DVDs, I also began to ask about how he managed his finances, in terms of the role his support staff took in decisions made about spending when he expressed a desire to purchase DVDs.

Using formal interviews as a research method allowed me to capture the perspectives of people after communicating my thoughts and ideas to them. Importantly, this method allowed me to learn about people's perspectives when they were individually given time and space to consider what I had asked them (O'Reilly, 2009). However, although my aim was to explore subjective realities, I also viewed these as contestable and partial, and so it was important that I did not necessarily take people's own accounts as fact, but instead as descriptions that gave me insight into their experiences (van Maanen, 2011; Silverman, 1993). As is described in the section above on p.102, these accounts were triangulated with the participant observation findings, which were collected throughout the fieldwork, to build up a layered picture of the complex interactions taking place.

I conducted 17 formal interviews with 18 people involved in the study. Interviews took place in locations that were convenient to the interviewees and lasted between 45 minutes and 103 minutes (see Appendix 5, Table A for full list of interviews and corresponding information). The individuals I requested to interview formally were people who I had made contact with during the research, but with whom I was not able to spend extended periods of time. This included managers at both Singertree Trust and Cambrick. Given that I was only regularly visiting one service within Cambrick, I decided it would be helpful to get a flavour of the other services this organisation provided, and so I interviewed a number of people from a range of services across this organisation. I also interviewed individuals from outside these organisations with whom I had made contact through a snowballing approach (Vogt, 1999), which I described in the field site section earlier in the chapter on p.98.

Three interviews took place in the very early stages of my fieldwork, all of which were recorded manually with written notes (one of these three interviews took place over the telephone). Although these interviews could have been audio recorded, I was initially concerned that an audio recorder may have discouraged some people from speaking candidly about their perspectives. However, I later decided that the benefits of an audio recorder, which would enable me to relay people's accounts verbatim, outweighed the risk that people might clam up at the prospect of being recorded. Moreover, because I conducted most interviews towards the end of the fieldwork, by this stage most of the individuals being interviewed had known me for some months and so I felt that their familiarity with me would likely supersede any discomfort they may have felt at being recorded. The decision to conduct the majority of interviews from the mid to end stage of the fieldwork was made so that I could enter into them with a firmer grounding of the ideas and themes I wished to discuss with people. However, the three interviews that took place early in the fieldwork were used in a different way as they provided me with an introductory sense of what was happening in the field, which I used as a broad guide during the early stages.

During the remainder of the fieldwork, I conducted 14 more interviews, of which 11 were recorded using an audio recorder. One person asked not to be recorded,

and so handwritten notes were made when interviewing them. The two remaining interviews took place whilst I was being shown around services and so it was not possible to record these. Instead, field notes were made after these interviews. I found this approach, of what has been described as 'walking interviews' (Evans & Jones, 2011) to be beneficial. Conducting the interviews 'on the move' (p.849) allowed me to gain a sense of how people's thoughts and words were being informed by the places through which we navigated, which gave me some insight of the services through the interviewees' eyes.

Using formal interviews and informal conversations flexibly was also an advantage as this allowed me to select an approach I felt to be most appropriate for specific participants and contexts, *i.e.* because the nature of my relations differed between senior managers, support workers and people with learning disabilities, different modes of communication were required depending on whom I was engaging with. For instance, I have already mentioned that non-verbal communication was helpful when interpreting the subjective realities of people with learning disabilities. To this end, as I have outlined above on pp.104-105, I felt that the more intuitive approach of informal conversation rather than formal interview would be best suited to people with learning disabilities. However, this is not to say that the more 'natural' conditions of informal conversations would enable all people to more accurately describe their beliefs and actions than would be possible in formal interviews. Rather, the use of both formal and informal interaction allowed me to build up a 'thick' layering of different accounts in different contexts (Geertz, 1973).

### **Analysis of empirical findings**

Due to the considerable amount of material that ethnographic fieldwork yields, in order to plausibly make sense of what I had experienced and observed, it was necessary to utilise tools to assist me in rigorously exploring and analysing the material with transparency (Emerson, Fretz & Shaw, 2011). The myriad of methods that I used to collect material during the ethnography required different analytical tools, and so it is necessary to describe how I utilised these in relation to the collected material.



Given the importance of the immersive nature of ethnography, I wanted to use analytical processes that enabled me to engage intuitively with the field. I felt that it was important to try, as much as possible, to continue the sensory experience of seeing the world through the eyes of the people into the stages of coding and analyses. This meant that I needed to utilise ways of coding and analysing that would allow me to retain a sense of the context in which the people and places were situated (Emerson, Fretz & Shaw, 2011). I felt that adopting an in-depth thematic analysis approach would give me with the freedom to achieve this (Boyatzis, 1998; Auerbach & Silverstein, 2003; Emerson, Fretz & Shaw, 2011), as this approach favours the 'summary and analysis of qualitative data through the use of extended phrases and/or sentences rather than shorter codes' (Saldana, 2009: p.208). Broadly, this involved reading and re-reading field notes and listening repeatedly to recorded interviews, during which time I would highlight text in field notes and make other notes around ideas and themes.

Before beginning the processes of engaged and in-depth analysis of field notes, during which concepts and themes would be built up, I used coding to systematically explore the written findings. Here, I refer to coding as 'the identification of topics, issues, similarities, and differences that are revealed through the participants' narratives and interpreted by the ethnographer. This process enables the ethnographer to begin to understand the world from each participant's perspective' (Sutton & Austin, 2015). There were several stages that made up the processes of coding. However, I did not adopt a strict instrumental set of guidelines to follow, which could be done for example by following a version of grounded theory (Corbin & Strauss, 1990). Instead, I interpreted coding to be an 'exploratory problem-solving technique without specific formulas to follow' (Saldana, 2009: p.8).

As field note entries were written, I underlined, put in boxes, highlighted, or capitalised words, phrases and descriptions of events I considered to be significant. At the end of each week of fieldwork I would re-read entries, and during this time I considered again areas that had originally been marked out as significant. I also returned to the other parts of the text that had not initially been marked as significant and considered whether anything had been missed in terms

of relevant concepts and connections with other information. From here, I worked on a separate document, writing short summaries and transferring phrases that were of significance.

In the very early stages of analysis these processes of basic coding were useful and essential in iteratively building up a picture, through words and descriptions, of the participant observation. As the participant observation progressed, I became aware that I was ready to begin engaging in more focused and defined conceptualising. After this, the processes of coding evolved into longer descriptions of concepts and themes, including connections and dissonances between these. It was essential that this move from basic coding towards in-depth conceptualising took place as it allowed me to keep the ideas and themes that were emerging interlocked within the context of the field rather than extracting them as discrete words and phrases (Emerson, Fretz & Shaw, 2011). The ideas that emerged from the participant observations and field notes both formed the basis of the semi-structured interviews and informal conversations, conducted towards the latter stages of the fieldwork, and were triangulated with them.

Again, the need to retain the findings within their emergent context shaped the way that I analytically approached the content of the interviews. Initially, I began coding and analysing the interviews I had recorded by hand, using thematic analysis (Boyatzis, 1998; Auerbach & Silverstein, 2003; Emerson, Fretz & Shaw; 2011). However, I found that working from transcripts removed my embodied experience of the contexts in which the interviews took place. Barbara Merrill and Linden West (2009) state that engaging with the written transcriptions is an important aspect of analysis when working with small extracts. However, for larger pieces of recorded conversation they contend that there can be 'a danger of unreadability, and getting lost in the detail of language use' (p.125). They go on to say that some 'aspects of an interview can get lost in transcription, including the music of speech as well as subliminal information' (p.125). Although Merrill and West suggest this can be countered by both listening to as well as reading transcripts, I have followed the approach taken by Sherryl Kleinman and Martha Copp (1993) who argue for the importance of engaging with the personal and emotional aspects of fieldwork. I argue that retaining these aspects during the

analysis requires one to relive, as much as possible, the nature of interactions during interviews, which could best be achieved by listening to the audio recordings. Indeed, this analytical stance could be aligned with Erving Goffman's approach to working with collected research material, when he comments that the point is 'not to, of course, just listen to what they talk about, but to pick up on their minor grunts and groans as they respond to their situation' (Goffman, 1989: p.125). Crucially, I felt that such 'grunts' and 'groans' could only have been experienced in aural form and so I listened to recordings repeatedly, writing down on a separate word document points of significance, connections or dissonances.

### **Developing the themes and overarching themes from the ethnographic material**

The processes of reflexivity and analysis commenced almost as soon as I entered the field and they continued, in an iterative manner, throughout the fieldwork and into the writing up of the thesis. This process of continual reflexivity and analysis was reflected in the writing of the field notes. Although, when beginning writing these at the start of the research, field notes were descriptive. However, in the very act of writing, I began to reflect on and analyse what I had been experiencing and interpreting in the field. This kind of dual process similarly took place when I was conducting participant observation, as in conjunction with interacting with people in the field, I was continually processing and interpreting the information in front of me. Some of these observations would be recorded in field notes immediately upon leaving the field. However, other observations required thinking about in more detail before committing them to paper for further analysis.

In between participant observation and writing of field notes, I analysed the written text of the field notes and listened to the interview recordings and triangulated these to build up thick layers of interpretation. I took an inductive approach to understanding the collected material (Roper & Shapira, 2000). To achieve this, all information gathered was repeatedly read and listened to throughout the research. As I read and listened, I would code and/or make notes as issues of interest or importance arose that related to the research question of how policy objectives were being experienced by people in everyday practice. As

new information was being collected, I would also go back to specific passages or recordings that appeared to connect with the new information, to see if valid connections or dissonances were there.

These codes and notes were then separated into groups, which were based around the following: when they occurred, the policy they related to, how I observed others interpret them, the conceptual theme/idea they related to and my own interpretation of this. Over time, these different groups came together to form a map of what I was observing and experiencing. When it felt appropriate, for the purposes of clarifying my own ideas, I would display these themes in visual diagrams. As well as providing clarity, this also helped me to build up a clearer picture of how groups fitted within the bigger picture of developing themes. Visual diagrams were made up of details pertaining to ethnographic material, which would then be assigned conceptual ideas. For example, a visual diagram pertaining to my experience of accompanying a participant to an employment training service was assigned a conceptual idea relating to economic empowerment.

After some time, the process of separating observations and interpretations into groups began to develop further and these groups began to form into defined themes, which eventually became overarching themes. An example of this process occurred in relation to the themes of responsibility and people with learning disabilities getting into trouble, which are discussed in chapter six. These themes were developed out of observations of some people with learning disabilities breaking the rules within their support settings and how this was responded to and framed by the staff supporting them. In triangulating these with my own observations and with wider literature, these themes were then connected to the broader concept of capacity, in terms of what this means for people with learning disabilities, and what this might indicate about relationships between citizens and the state within the context of social care. The themes developed from these processes were then taken back into the field to see if they matched with what was occurring. If they were found not to, I assessed why this might be. For instance, whether the occurrence I recorded was an isolated, but legitimate interpretation, or whether I had misunderstood what had been

observed. These processes of developing ideas and themes occurred continually throughout the fieldwork.

### **Chapter conclusion**

In this chapter I have justified and outlined my methodological approach, showing how this is theoretically underpinned by a subjective notion of reality. I have also described how the fieldwork was conducted using an ethnographic approach and the findings analysed. The next chapter is the first of three chapters that present the empirical findings. Chapter four serves as an introduction to the field sites, and describes some of my experiences of first visiting these places. Then, chapters five and six respectively present the ways in which people with learning disabilities and support staff experienced the implementation of policy objectives in everyday support settings. Here, I show how there was a clear divide between people with learning disabilities and support staff, which impacted the collection and analyses of findings, and explains the decision to present these experiences in separate chapters. Yet, despite their radically different views and behaviours, the lives of people with learning disabilities and support staff were deeply enmeshed with each other. Given this, across chapters five and six the experiences of people with learning disabilities and the people supporting them overlap with each other. In the following chapters, I attempt to triangulate these findings with each other and my own interpretations to present a picture of what was happening in these contexts.

## Chapter four

### Introduction to the empirical chapters

#### Introduction

This chapter serves as an introduction to the main field sites that were involved in the research – those in which I spent most time. At Cambrick this included the Hilltop Mews day centre, whilst at Singertree Trust I spent much of my time at the residential care home, Chatsview Road, the supported living property, Sanderstead View, as well as the employment training services, Pigtree and Goatsgruff farms. I will also describe the locations associated with the independent community organisations with whom I spent some time, including the advocacy service, Hear Us, and the church community project, Station Park Café. Where necessary, I also draw on my field notes that describe my experiences of visiting these places for the first time. Given that these places arguably tended not to be accessible to the general public, nor were they places of choice to visit for people who were not receiving support or working within them, these initial reactions to the sense of difference I experienced upon entering them would become important in the interpretation and analysis of my overall fieldwork experiences. I hope that setting the scene in these ways will assist the reader in understanding the particular context of this study.

*'During my first walk from the train station to Chatsview Road this morning, I saw a road-sign directing the way back to the town from where I had just come. Where I lived. This sense of being caught between a cross-road of, on one side, an entirely familiar and safe place, and on the other, an unknown world, was palpable. For me, it perfectly represented the sense of trepidation I was feeling. I longed to veer off course, to return to where I had come from, avoiding this unknown and uncertain place in to which I was about to enter' (field notes, July 2014).*

Given the way that a learning disability can impact people across their lives it is arguable to expect that, in some ways at least, the lived experiences of people with learning disabilities will be different from those of people without this condition. This sense of difference was indeed something that I anticipated upon entering people's lives through my fieldwork. I have provided the field note extract above as a way of illustrating this and the feelings of discomfort it invoked. Indeed, when entering the field it did at first feel akin to moving into what seemed like another world. Though in fact my fieldwork research was conducted within my own society, indeed, to some extent, within parts of a community I am familiar with, the social worlds of the people I spent time with appeared, in some ways, to be worlds apart from my own.

The following sections below aim to further convey these experiences, as I provide details on the material set up of the places in which I spent time, as well as some of my first impressions upon entering them. Before presenting this, however, the following tables (see Table 4.1 and Table 4.2) provide details of the main fieldwork sites and the services provided in these, as well as a list of all people who were involved in the ethnography.

**Table 4.1.** List of organisations, fieldwork locations and descriptions of services.

Organisation pseudonym	Fieldwork location pseudonym	Description of Service(s)
<b>Singertree Trust</b>		A national (but based predominantly across the South of England) registered charity providing housing and day service support for adults and children with learning disabilities and/or autism.
	- Viewpark Centre	Head office.
	- Chatsview Road	Residential care home.
	- Sanderstead View	Supported living home.
	- Bristlehedge	Day centre and employment training service.
	- Pigtree Farm	Employment training service.
	- Goatsgruff Farm	Local community organisation providing therapeutic working environments for people with learning disabilities.
<b>Cambrick</b>		Based within an area of South West England, a not-for-profit social enterprise, funded by the NHS and local authority. Providing a range of health and social care services in the community for people with learning disabilities, as well as other groups.
	- Hilltop day centre	Providing therapeutic interventions for people with learning disabilities, including support with communication, physical health and wellbeing, as well as support with developing daily living skills and confidence. Specific activities include, arts and crafts, gardening and health therapies, such as hydrotherapy and physiotherapy.
<b>Station Park Café</b>	- Station Park Café	A café run in conjunction with the adjacent church, providing volunteering opportunities to people wanting to become part of their community. Volunteers mostly made up of older people and people with learning disabilities.
<b>Hear Us</b>	- Head office - Station Park Café - Various community locations	An independent advocacy service working primarily with people with learning disabilities to support them to have a greater say in their lives and communities.
<b>In The Community (I.T.C)</b>	- Station Park Café - Various community locations	A registered company set up and run by people with learning disabilities and supported by advocates from Hear Us advocacy service.



**Table 4.2.** List of participants, the organisation they belong to, their status and role. Participants who were core to the study are shaded grey.

#	Pseudonym	Organisation	Location	Status	Role
1	Patrick Jones	Cambrick	Hilltop Mews day centre	learning disability	day centre attendee
2	Fred Davies	Singertree Trust	Chatsview Road	learning disability	lived at property
3	Kevin Patterson	Singertree Trust	Chatsview Road	learning disability	lived at property
4	Pamela Jones	Singertree Trust	Chatsview Road	learning disability	lived at property
5	Rebecca Smith	Singertree Trust	Chatsview Road	learning disability	lived at property
6	Ray Winder	Singertree Trust	Chatsview Road / Goatsgruff Farm	learning disability	lived at property, worked at farm
7	Sam Treadwell	Singertree Trust	Sanderstead View	learning disability	lived at property
8	Joey Tammer	Singertree Trust	Sanderstead View / Pigtree Farm	learning disability	lived at property, worked at farm
9	Mark Whyatt	Singertree Trust	Sanderstead View / Pigtree Farm	learning disability	lived at property, worked at farm
10	Julie Davies	Cambrick	Hilltop Mews day centre	staff	day centre manager
11	Fred Peck	Cambrick	Hilltop Mews day centre	staff	locality manager
12	Jo Parry	Hear Us	head office / Hear Us / I.T.C events	staff	owner/manager, lead advocate
13	Sheila Biggins	Hear Us	Hear Us / I.T.C events	staff	advocate
14	Rachael Patrick	Singertree Trust	Chatsview Road	staff	house manager
15	Amanda Wells	Singertree Trust	Chatsview Road	staff	support worker
16	John Robbins	Singertree Trust	Chatsview Road	staff	support worker
17	Linda Watson	Singertree Trust	Chatsview Road	staff	support worker
18	Lucy Larley	Singertree Trust	Chatsview Road	staff	support worker
19	Sandra Lang	Singertree Trust	Chatsview Road	staff	support worker
20	Shaun Range	Singertree Trust	Chatsview Road	staff	support worker
21	Trish Larks	Singertree Trust	Chatsview Road	staff	support worker
22	Nigel Sutton	Singertree Trust	head office, Viewpark Centre	staff	locality manager
23	Sarah Hill	Singertree Trust	head office, Viewpark Centre	staff	operations manager
24	Jane Davies	Singertree Trust	Pigtree Farm	staff	support worker
25	Samantha Hake	Singertree Trust	Pigtree Farm	staff	support worker
26	James Walter	Singertree Trust	Sanderstead View	staff	support worker
27	David Smith	Singertree Trust	Sanderstead View	staff	house manager
28	Emily Gillies	Singertree Trust	Sanderstead View	staff	support worker
29	Doris Armstrong	Singertree Trust	Sanderstead View / Chatsview Road	staff	support worker
30	Steve Connors	Station Park Café	Station Park Café	staff	support worker
31	Victor Jones	/	Chatsview Road	/	manager, outreach/community development worker
32	April Whyatt	Singertree Trust	Sanderstead View	/	husband of Pamela Jones
33	Geordie Murray	/	Hear Us / I.T.C events	learning disability	Mark Whyatt's mother
34	Maggie Taylor	/	Hear Us / I.T.C events	learning disability	attendee
35	Trudy Samuel	Cambrick	Hilltop Mews day centre / Hear Us / I.T.C events	learning disability	attendee
36	Paul Churchwood	community college	college campus	learning disability	student

(Table 4.2. ... continued)

#	Pseudonym	Organisation	Location	Status	Role
37	Stuart Bailey	community college	college campus	learning disability	student
38	Sophie Holland	I.T.C	Hear Us / I.T.C events	learning disability	member
39	Don Parker	Singtree Trust	Chatsview Road	learning disability	lived at property
40	Ethel Williams	Singtree Trust	Chatsview Road	learning disability	lived at property
41	Robert Prince	Singtree Trust	Sanderstead View	learning disability	lived at property <sup>s</sup>
42	Linda Shrew	Singtree Trust	Singtree Trust national event	learning disability	attende
43	Janet Leyes	/	/	staff	freelance advisor
44	Sally French	/	/	staff	freelance advisor
45	Eric Williams	Cambrick	Cambrick head office	staff	clinical commissioning group
46	Helen Saunders	Cambrick	Cambrick head office	staff	clinical commissioning group
47	Anna Dunn	Cambrick	Cambrick head office	staff	speech and language therapist
48	Catherine Smith	Cambrick	Employment Now training office	staff	job coach
49	Andrea Chappell	Cambrick	Hilltop Mews day centre	staff	support worker
50	Samira Haddad	Cambrick	Hilltop Mews day centre	staff	support worker
51	Siobhan O'Brien	Cambrick	Hilltop Mews day centre	staff	support worker
52	Phillip Brown	Cambrick	Linsfield day centre	staff	day centre manager
53	Samantha West	community college	college campus	staff	support worker
54	Hilary Scott	community college	college campus	staff	teacher
55	Jane Harvey	Goatsgruff Farm	local community organisation	staff	support worker
56	Kate Johnson	Goatsgruff Farm	local community organisation	staff	support worker
57	Susan Howie	Goatsgruff Farm	local community organisation	staff	support worker
58	Trevor Bond	Goatsgruff Farm	local community organisation	staff	support worker
59	Harry Sheers	Hear Us	Hear Us / I.T.C events	staff	advocate
60	Hatti Staple	national learning disability charity	/	staff	chief executive
61	Pam Jenkins	national learning disability organisation	Hear Us event (guest speaker)	staff	program lead
62	Hannah Stokes	Singtree Trust	Bristlehedge	staff	locality manager
63	Frank Gardener	Singtree Trust	Bristlehedge	staff	support worker
64	Julie Collin	Singtree Trust	Chatsview Road	staff	support worker
65	Graham Willis	Singtree Trust	head office, Viewpark Centre	staff	job coach
66	Michael Roberts	Singtree Trust	head office, Viewpark Centre	staff	job coach
67	Jan Anderson	Singtree Trust	Pigtree Farm	staff	locality manager
68	Alexandra Bishop	Singtree Trust	Sanderstead View	staff	part-time support worker

<sup>s</sup> moved out of property prior to start of fieldwork.

### **Cambrick: Hilltop Mews**

Hilltop Mews was a day centre belonging to Cambrick where I visited one core participant, Patrick Junes. Hilltop Mews was situated at the top of a hill within a small former industrial town, which was a 30-minute bus journey from one of the cities in which my fieldwork sites were based. The day centre itself was a single-storey building, covering a fairly large site. Entering the building, I was first met with the front of house reception desk with receptionists behind it. Upon arrival, all visitors were required to sign the visitors' book, and then asked to wait in the near-by seating area. During an early visit to Hilltop Mews, I had come to meet with the centre's manager, Julie Davies. Whilst I was sitting in the waiting area, I observed several people with learning disabilities walking back and forth past the reception area – some passed straight through without stopping, whilst others stopped to engage the receptionists in conversation. I also noticed that, at times, they would look briefly at me. Admittedly, I felt a sense of fear and unease about being in this kind of environment, yet I was also keen to present a relaxed and comfortable image, trying to offer a smile if someone made a cursory glance in my direction.

As Julie came to collect me from the reception area, she introduced herself and directed me towards the short walk to her office. In this moment, a man with learning disabilities walked passed us both, greeted Julie and then distinctly glanced at me. Later during our meeting, Julie remarked on this, saying that she had observed how the man had looked at me. She went on to say that because of how I look, she needed to be careful about who I could spend time with (field notes, July 2014).

During this visit to Hilltop Mews, I had only been provided access to the front of house area, as Julie's office was close to the reception. However, from this brief contact I felt that the building and services provided appeared to be what might be recognised as distinctly institutionalised. Following later visits to the day centre, when I would spend time with Patrick Junes, this sense that the service followed an old-fashioned format continued.

### **Spending time at Hilltop Mews**

Julie had organised for me to spend time with Patrick, who was in his mid 40s, was severely physically and intellectually disabled and a wheelchair user. During my first day spent with Patrick, I joined him and some other people whilst they were partaking in a game of curling (using wooden discs). I observed that people seemed to be sitting around and did not appear to be stimulated. I remember thinking that this was how I imagined a day centre for older people might look and feel.

Within Hilltop Mews itself, there were different rooms with different activities taking place throughout the day, such as cooking, gardening, painting and craft. The walls inside the building were decorated with things that people had taken part in at the centre, for example, art works and photographs cataloguing activities. There was also a timetable of the running order of the day, detailing which activities each person was doing each day, along with their photograph and a photograph of the member of staff who was supporting them. Despite this old-fashioned and perhaps segregated feel I experienced at the beginning of the fieldwork, as time went on I remember gaining a sense that both people with learning disabilities and the staff supporting them here appeared to be happy. Indeed, the sense of comfortability people felt with each other appeared to be reflected in their relationships, as both people with learning disabilities and staff interacted with each other in friendly, informal and, at times, caring ways, such as through hugging.

Patrick attended Hilltop Mews every day and was supported by three permanent support workers. I visited Patrick one day per week during my fieldwork, but as his daily activities varied throughout the week I tried to visit him on different days, in order that I might get a sense of how his support was being provided over the long term. Generally, visits consisted of meeting with Patrick at Hilltop Mews at around 10 a.m. The morning would begin with communal tea and coffee time, after which support staff would divide people into smaller groups in order to take part in the various activities. These would continue until lunch, which was another communal activity involving the whole centre. As Patrick was severely physically and intellectually disabled, he received a substantial funding package. This

allowed him access to several health-related services, including physiotherapy and hydrotherapy, both of which he attended as part of his day placement activities at Hilltop Mews. Physiotherapy and hydrotherapy were not available on the Hilltop Mews site, and so two days per week Patrick was accompanied by two of his permanent support workers to these services.

Although I considered Patrick to be a core participant who influenced my interpretation of the field, findings collected during my time spent with him and the staff supporting him are not explicitly included in empirical chapters five and six. There are two main reasons for this. Firstly, because I was visiting Patrick only once a week during the course of the fieldwork, I found that gaining a rich and in-depth understanding of his and his support workers' lived experiences was very challenging. As such, I have felt reluctant to make claims about these experiences in the same way that I have with people with whom I had spent longer periods of time. This limited time factor was compounded by the severity of Patrick's condition, which also meant that getting to know him well was a complex process – he could speak, but only a limited amount of words, and getting used to his enunciation of words required spending time with him over a long time-scale. Secondly, Patrick's condition and his care and support were unique amongst the other participants in the study. This, combined with the fact that Patrick was the only person I visited at Cambrick, has posed difficulties for me in fitting him into the empirical chapters in ways that do not feel clunky and out-of-place. In order that I might do the findings from the time I spent with Patrick and his support workers more justice, I hope to explore these observations and experiences elsewhere outside of this thesis.

### **Singertree Trust: Sanderstead View and Chatsview Road**

On the day I first visited Sanderstead View and Chatsview Road, I travelled to Singertree Trust's head office, Viewpark Centre, to meet with the operations manager, Sarah Hill. Here she introduced me to one of her locality managers, Nigel Sutton, who would help me to access the services in this organisation. As a locality manager, Nigel managed Singertree Trust's housing services that were located within a designated area. His role here was to ensure that the needs of

people with learning disabilities were being met through their housing support. He was also responsible for the needs of staff working with the services covering his locality. Sarah advised me that Nigel would take me to meet the people with learning disabilities and staff at two of their services, Sanderstead View and Chatsview Road. From this point, Nigel became a significant person in the research, and throughout my fieldwork I formally interviewed him twice to discuss what I had been observing and experiencing within the services at Singertree Trust.

The first house that Nigel took me to visit was Sanderstead View. As I described in chapter three on pp.97-98, Sanderstead View was a supported living home. As well as this, however, I was also told by Sarah Hill that it was what Singertree Trust had termed a transitions house. Sarah described this house as an experiment within Singertree Trust as it was the first type of service they had provided that was specifically aimed at supporting young people as they made the transition from children and young people's services to adult services. The creation of this service at Singertree Trust was in recognition that this transition is well documented as being a crucial yet difficult stage to get right (Patton & Viner, 2007). This is thought to have been due to the historical lack of structural support provided to people and their families during these times, which has meant these periods have often been difficult and disruptive for the individual transitioning, as well as for the families involved (Care Act, 2014). With their transitions house, Singertree Trust were trying to improve these outcomes.

At the time of conducting my research, between two and three young men were living at Sanderstead View: Mark Whyatt, aged 24, along with Joey Tammer and Sam Treadwell who were both 27. All three of these young men became core participants in my research. In addition to the young men there were also permanent staff members, including one house manager, James Walter, and two permanent support workers, David Smith and Emily Gillies, all of whom also became core participants. During the drive on the way to Sanderstead View, Nigel told me that the young men living there were particularly interesting because they raised "many complications in relation to the Mental Capacity Act" (field notes, 21<sup>st</sup> July 2014). This was, he said, because although they had all been assessed

as having capacity, they still required significant support with various aspects of their lives. With this, Nigel began telling me about one young man who was just about to move out of the property, Robert Prince (who had already left before I began fieldwork at the house). Robert was a Type 1 diabetic, and although very intelligent, had stopped monitoring his diabetes. Nigel said that though he believed Robert had capacity to understand the implications of not controlling his condition, this capacity to understand remained very much dependent upon who and how people interacted with him. Yet, despite this Nigel also said that it was important that the young men living at Sanderstead View were given the opportunity to live like other young men their age – with other people of a similar age and with the social freedoms that a young person might expect or want from life.

Sanderstead View was situated on a quiet road within an economically disadvantaged area of one of the cities where much of my fieldwork was conducted. Upon first arriving at the property leading up to the front door I observed that it appeared to be a conventional home-like building. When we arrived at the front door, Nigel took me directly inside as the door was open. The house itself seemed quite empty and immediately upon entering I remember feeling a sense of there being a distinct lack of homeliness. I observed that the décor was quite out-dated and not what I would typically associate with the choice of young men; it seemed to resemble that of a cheaply renovated property which served little purpose other than being 'a roof over one's head'. Although during this first visit I did not enter the upstairs of the property, during later visits I observed how the starkness increased up here as there was a bare stairway which led to several fire-proof doors, behind which were the staff office, staff bedroom, and bedrooms of people living there.

During this first visit, we found that only one person with learning disabilities, Mark, and one support worker, Emily, were there. The other housemates, Robert, Sam and Joey were all out and wouldn't be back for a while. Mark appeared pleased to see Nigel, and quickly launched into a discussion with him about the recent football results, as well as relaying to Nigel TV programmes he had recently been watching. The support worker, Emily, also appeared engaged and

interested in the conversation. During this conversation, I felt a slight sense of awkwardness, as I couldn't understand much of what Mark was saying, and was forced to rely on Nigel to repeat for me what Mark had just said. After a short while, Nigel introduced me into the conversation, explaining to Mark who I was and asking him if he would be happy for me to come and spend some time with him and the others in his house, to see how they all lived together. Mark's response to this question was of immediate agreement.

As this conversation took place, I noticed how Nigel described to Mark that my being there would be an opportunity for him to do different activities out of the house. This appeared to echo what I mentioned in chapter three on p.85, that I would be beneficial to the organisation because I would be there to "help-out" and act as "an extra pair of hands". Certainly, as the fieldwork progressed, I began to see that many of the support workers also saw my presence as an opportunity to provide more one-to-one time to the people they were supporting, as well as to offer them the opportunity to go out, for instance, into town or to the cinema. An interview with Nigel later in the fieldwork also confirmed this when he explained that, because of the very few hours of support that were funded to some people with learning disabilities, staff simply did not have the time to spend with them. As such, Nigel felt that my presence there was a real benefit to "the guys" (interview, 8<sup>th</sup> September 2014).

While we were still at Sanderstead View, Nigel began telling me about one of the other young men living there, Joey Tammer, who had only moved into the house three weeks previously. Nigel had asked the support worker, Emily, if Joey was out alone, to which she replied that he was. Nigel then started explaining to me that, because they were still getting to know Joey and the level of support he required, it was difficult for staff to make judgements about whether, if at all, to telephone his mobile to check that he was ok when he was out alone (field notes, 21<sup>st</sup> July 2014). Nigel then said that he would take me on to the next house, Chatsview Road, which was a few minutes' drive away and so also located within the same area.



Sarah Hill had described Chatsview Road as being quite a different set-up to Sanderstead View. It was a registered care home (residential care), but at the time of conducting this research was in the process of waiting to be de-registered to become a supported living home. As this property was in the process of transferring to a supported living service, Sarah Hill appeared keen to show how their organisation was evolving in accordance with policy aims of moving towards this model of living.

Upon arriving at Chatsview Road for the first time, I observed it to be a large residential property with a large drive-way and situated on a main road. I would later discover that the building itself had originally been two semi-detached houses, which had subsequently been renovated by Singertree Trust into a single house (though the property still had two front doors). Upon entering the house and moving through the hallway and into the kitchen area, which also doubled up as a seating area encompassing two large sofas, I immediately felt that this property appeared to be homelier than Sanderstead View. Though this may have been because it had more items, such as furniture and ornaments, which made it feel more like what I would describe as a conventional home. However, as with Sanderstead View, during later visits to the property, upon venturing upstairs, I felt as though any sense of what I would consider to be homeliness was washed away in the stark corridors and rows of fire-proof doors.

Whilst conducting my research, between six and seven people lived at Chatsview Road, aged between 31 and 77 years, all of whom were described as having higher needs than those living at Sanderstead View (see Table 4.2, pp.116-117 in chapter four for list of people with learning disabilities living at Chatsview Road). Nigel explained that he felt two individuals, Ray Winder and Rebecca Smith, would be good for me to work with. Ray was a 77-year-old man, and Rebecca a 31-year-old woman. During this first visit with Nigel, we were met by two members of staff, the house manager, Rachael Patrick and a support worker, Amanda Wells. Ray was at home, but Rebecca was not and so after agreeing that another date would be arranged for me to meet Rebecca, I explained my research to Ray. Nigel then suggested to Ray that he show me around the house. Ray first showed me his bedroom (which was on the ground floor) and then took

me out to the garden where he kept a shed with an array of tools, along with a growing vegetable patch containing potatoes and onions. After leaving Chatsview Road that day, Ray handed me some onions and potatoes from his garden, instructing me to eat them when I got home (field notes, 21<sup>st</sup> July 2014).

Similarly to the meeting with Mark at Sanderstead View, I also felt slightly awkward when speaking with Ray because I was unable to discern much of what he was saying. This difficulty was one that I would initially experience with many of the people with learning disabilities with whom I spent time during the fieldwork. On reflection, this issue was an important signifier in that, as fieldwork progressed, I began to be able to discern what people were saying without the need for interpretation from staff members. In this sense, these times could be seen as indicative of turning points in my experience in the field, as becoming familiar with people's speech felt like an important 'rite of passage', helping me to feel, in a deeper way, that I was 'part of the group'.

### **Spending time at Singertree Trust**

At both Chatsview Road and Sanderstead View, I began the fieldwork by spending time with people during their one-to-one hours and whilst they attended day placements. One-to-one hours are allocated times when people with learning disabilities are supported by one member of staff, the aim being that their support is personalised. During these early stages of fieldwork, I would usually arrive at people's homes at around 8 a.m., so that I would be ready for when their one-to-one support would begin, or so could travel with them to their day placement. I would usually spend the entire day with people, returning with them to their homes after their day activities had finished.

People's one-to-one hours usually consisted of taking part in leisure activities, such as going into town for coffee, clothes and toiletries shopping, or to bowling or the cinema, which I mostly did with Rebecca Smith at Chatsview Road. For Mark Whyatt and Joey Tammer at Sanderstead View, as well as Ray Winder at Chatsview Road, their placements involved working at farms. To this end, a substantial amount of my fieldwork during the first few months was spent working

on allotment and gardening sites. The times spent with people during their daily activities were, by their nature, task orientated, which meant that I could slot myself into the things taking place, such as gardening.

Mark and Joey worked at Pigtree Farm, which was part of Singertree Trust and was first established through one of the long-stay hospitals. Since the closure of the hospital it had been attached to, it had become a working farm 'providing vocational and employment training for people with learning disabilities and autism' (reference not provided for anonymity purposes). Pigtree Farm was intended to be a setting where people could contribute to the functions of a working farm whilst developing their individual workplace skills and improving their health and wellbeing. There was also opportunity here for people to move on to paid employment within the service, with the landscape gardening team. Whilst spending time with Ray at Goatsgruff Farm, I learnt that it was a separate organisation to Singertree Trust, and had been established as part of a long-term project with a mission to engage the local community and develop knowledge about the importance of green spaces. As part of this, the farm described itself as providing a safe environment for 'training placements and therapeutic activities in horticulture and animal care for people with learning disabilities and mental health concerns' (references not included for anonymity purposes). For Mark and Joey, young men in their 20s, their work at the farm was focused around employment training. Whereas for Ray, who was in his 70s, farm work was used as therapeutic support.

Meeting people at their homes also meant that I had access to the times when the whole house tended to be present – during mornings and late afternoons. This time spent in people's homes provided me with a glimpse of what was happening in these settings. My time here mainly consisted of sitting on sofas in the kitchen/living areas, or helping out with supporting people and doing chores around the house. Both Chatsview Road and Sanderstead View had large communal areas, and whenever I arrived at each, my visits would be overwhelmingly spent in these spaces.

By the time I had arrived at the mid-stage of fieldwork, however, I was keen to experience the services from a different angle. I had found that the visits to people's homes before and after day placements were intriguing snippets of what was happening between the support workers working there and people with learning disabilities. I had also begun to sense that I was not getting enough access to the perspectives and actions of support workers who were working at Sanderstead View and Chatsview Road, which I was keen to explore further. The period of fieldwork conducted in people's homes, although physically easier than accompanying people to day placements, was in other ways, more difficult. When in people's homes, finding a role for myself was tricky. For instance, during the hustle and bustle of activities during the mornings I was aware that I did not want to slow things down or get in people's way. Where possible, I would attempt to 'help-out', for example, with supporting people to make their breakfast or get ready for their day ahead. At other times, when the properties were quiet, I felt it difficult to justify my presence. During these times, I also felt that some support workers were wary of me, as if I was watching or assessing them.

### **Independent community organisations**

During a conversation with Fred Peck, the locality manager at Cambrick, he mentioned that he thought it may be useful for me to spend some time with the independent advocacy organisation, Hear Us. This organisation provided an advocacy service in the local area. Following this recommendation, I contacted Jo Parry, the owner and manager of Hear Us, and requested to meet with her to discuss the services that her organisation provided. Hear Us, which was established in 2001, described itself as 'a service which supports individuals and groups to have a greater say in their lives and communities' (reference not included for anonymity purposes). Individuals with learning disabilities who accessed Hear Us services lived in the immediate and surrounding areas and were supported by a range of provider organisations. They included people with learning disabilities across a range of ages, from late teens to mid-60s, and with a range and levels of need.

During my time spent with Hear Us I also learnt that, in 2012 the local authority had commissioned them to support some people with learning disabilities to set up their own social enterprise called, In The Community (I.T.C). The I.T.C described itself as a:

‘registered company set up and run by people with learning disabilities who are all members of the [name of local authority] Networks, supported by advocates from Hear Us. ... The I.T.C is a group of 12 people with learning disabilities who are learning how to run their own business – in the future the I.T.C want to be able to run the company without help’ (reference not included for anonymity purposes).

In conjunction with advocacy support, Hear Us also supported the I.T.C to hold a number of monthly social events for people with learning disabilities living in the surrounding areas. As well as to hold regular meetings where members discussed organisational aspects of their business, such as its function in the local community and how they could contribute to the community for people with and without learning disabilities. As part of my fieldwork, I attended some of these meetings and events.

Whilst spending time with Hear Us and the I.T.C, Jo Parry told me about Station Park Café where Hear Us and the I.T.C held some of their events. Station Park was managed by Steve Connors who was an outreach/community development worker. It was a church project that offered outreach services to people in the community who were, in varying ways, socially isolated and/or in need of a safe space in which to spend time and contribute to the running of the café. Part of this included employing, in paid or voluntary capacities, people with learning disabilities. The café described itself as providing:

‘a welcoming place where people of all ages can meet together with food and drink [it is] a Fairtrade venue with strong links to social concern, peace and justice organisations’ (reference not included for anonymity purposes).

The café was connected to the church in the centre of one of the cities in which my fieldwork was carried out. The café itself was a large space with several tables, a large counter area and a play area for young children. The interiors of the café were open-plan and functional, similar to a canteen. Upon entering inside I found it to be a very warm and welcoming place and it was immediately apparent that a range of different people spent time here. As well as people with learning disabilities, I observed how older people, mothers with young children and homeless people used the café as a place to connect with the community.

In returning to my descriptions at the beginning of this chapter, of how entering these settings felt alien to me, it is important to point out that after some time, I also observed how my feelings of unease about people's behaviour almost always dissipated once I had become familiar with them. With this, these settings began to take on for me a sense of 'normality', as I gradually grew to understand the ways people engaged with each other and the world around them. However, when reflecting on my experiences of these settings, the inescapable sense of these settings being a different world, even of a different reality, remained. Even down to everyday actions I observed taking place, such as the bodily movements and noises that some people with learning disabilities made, could seem so removed from other aspects of life.

This sense of difference was marked in a physical sense too, by how the homes and the places where people with learning disabilities spent their days were often set away from the centre of towns or cities. Many leisure activities with people were spent in places that were located slightly outside of town centres, for example bowling alleys at industrial parks, or small local shopping centres which were dominated by shops selling low-priced goods. Pursuits undertaken as part of social care support also tended to be in places set away, for example Hilltop Mews day centre was located on the top of a hill just outside a former industrial town. Elsewhere, Viewpark Centre, Singertree Trust's head office, which also served as a hub for many support services taking place through the organisation, was a former secondary school and situated on the outskirts of a large city centre. Indeed, as the fieldwork progressed, I began to develop a deep sense of how

people with learning disabilities were living isolated lives. Although they were based in what could be described as community locations, they appeared to me to locate quite different existences within these places, as if they were in a constant state of 'betwixt and between' the reality of the care settings and that of the outside world.

### **Chapter conclusion**

In this chapter, my aim has been to set the scene for the empirical chapters to follow. In doing so, I have attempted to provide an initial flavour of both the material and social fabric of the places in which the fieldwork was conducted. Although initially these places and the people in them appeared to me as rather alien, as time went on and the fieldwork progressed the sense of difference that I felt began to fade and the things I was witnessing and experiencing began to take on a sense of normality. Further still, as my relationships with people involved in the research developed I began to feel connected to them, despite our worlds being so far apart. Yet, notwithstanding these feelings of connection I felt during the fieldwork, through reflection of my experiences I also developed a deep sense of how separate the lives of many people with learning disabilities remain. It was through ethnography that I could achieve this level of immersion and reflective analysis, and I hope that the findings presented in the chapters to follow are able to do justice to the deep insight that this approach afforded me.

## Chapter five

### How people with learning disabilities experienced the implementation of government policy objectives

#### Introduction

In this chapter, I present the ethnographic findings which detail how people with learning disabilities experienced policy objectives through their social care support. Through this, I show how they expressed differing expectations to their support workers and other staff members towards the support they received. Support workers and other staff were being instructed through policy to provide support in ways that promoted people's independence and community inclusion. Whilst people with learning disabilities did express awareness of and desires for autonomy, they also tended to seek emotional and personal interactions from the people supporting them. In addition to this, at times, it appeared that the expectations made of people with learning disabilities, in terms of the rights and responsibilities that accompanied aspirations of independence and community inclusion, were set beyond what they were able to achieve. In the context of everyday practice, these differing expectations emerged as points of tension and conflict between people with learning disabilities and support workers/other staff. I explore these tensions and conflicts through the following themes of care plans; state-led community participation; non-state-led community participation; college courses; paid employment and employment training services; and economic value versus human value.

*"I might get a girlfriend next year. I want to go and find one."* (Mark Whyatt, 13<sup>th</sup> November 2014).

*"I don't think he can make the choices what he wants. He's not like an adult like us. We know what we're gonna do each day, Mark don't."*



*And, I think he finds days when he gets really frustrated sometimes.”*

(interview, April Whyatt, Mark Whyatt’s mother, 7<sup>th</sup> February 2015).

## **Care plans**

As I have described in chapter four on p.121, Sanderstead View, a supported living home within Singertree Trust, was one of my core fieldwork sites. I also described here that whilst conducting my fieldwork, there were up to three young men with learning disabilities living at Sanderstead View: Mark Whyatt, Joey Tammer and Sam Treadwell. The young men were supported at Sanderstead View by three permanent members of staff; the house manager, James Walter, and the support workers, Emily Gillies and David Smith.

Mark, who was 24, had been living there for four years. During an interview with Mark’s mother, April, she told me that it had been her decision for him to move into Sanderstead View. She explained how she had felt that his behaviour had become unmanageable in his previous accommodation at residential college – there he was increasingly anxious and sometimes became violent. Whereas now, she felt that the staff at Sanderstead View worked well with Mark and she described how, though the house manager, James, would ask her permission when Mark wanted to make large financial purchases, on a day-to-day basis she was happy for the staff to take the lead with Mark’s support (interview, 7<sup>th</sup> February 2015).

Joey Tammer, who was 27, had moved into the house about two months after I began my fieldwork. He had arrived at the house from a residential care service, also run by Singertree Trust. The staff at Sanderstead View told me that Singertree Trust had decided to move Joey because his previous place was not viewed by Singertree Trust or Joey himself as suitable for him – he had been living with people much older and this service was viewed as too restrictive for him. Joey was in contact with his family and would arrange to visit and/or meet with his parents a few times per month, but he did not appear to be dependent on them for financial decisions.

Sam Treadwell, also 27, had been living at Sanderstead View since the service began at this house, around five years ago. He was described by the support workers as “the last original” in that the other people who had moved into the house with him when the service first began had since moved out. Sam also had a family who continued to be involved in his life. Including supporting him financially, he also spent time with them socially. His parents appeared to play a significant role in his support, for instance, if Sam wished to make a large purchase, the support staff at Sanderstead View would seek approval from Sam’s parents. It was also his parents’ decision that Sam move out of Sanderstead View – which happened mid-way through my fieldwork – into the nearby area. This decision was made because his new property was closer to his daytime and evening activities. As well as this, the flat Sam would be moving into worked on the basis of fewer support hours than Sanderstead View, and so this move was seen as a step forward for Sam.

Whilst spending time at Sanderstead View, I observed how care plans were used by support workers and people with learning disabilities. At the property, all the care plans were kept in the house office. They were used to keep written records of people, for example, their banking details and the hours of support for which they had been funded. The plans also provided character profiles of people, for example, of people’s likes and dislikes. In accordance with this, I observed how care plans were presented in ways that represented the views of the person themselves. One obvious indicator of this was that care plans were written in the first person. Indeed, when I read through Mark and Joey’s care plans, it was outlined in both that the plans had been produced with their “full involvement” (field notes, 17<sup>th</sup> December 2014). Mark’s care plan also stated that he said, “I can sometimes buy things I don’t really need”, and so he needed to be supported with his spending (field notes, 17<sup>th</sup> December 2014). During my time spent at Sanderstead View, Mark would continually ask support workers if they would take him out or if he could go shopping. For instance, he regularly wanted to go into town and play pool, or to buy DVDs and books. Much of the group conversations at Sanderstead View revolved around Mark asking the staff in his house for these kinds of things.

On the first day I went out alone with Mark, we went bowling. Afterwards, he told me that he wanted to buy a wrestling DVD, so we went to Sainsbury's to see what they had. I observed how Mark became very excited when looking at the DVDs on the shelves, he was speaking and moving in very animated ways. After a short time of looking, he found a DVD for £20. He had enough money for this, but, given that this was our first time together alone, I felt uneasy about agreeing to his purchasing it and so telephoned the staff at Sanderstead View to see if this was allowed. Support worker David told me not to let Mark purchase the DVD and to tell him that the weather had turned bad and so it was time to go home. I then suggested to Mark that he think about the purchase as he could always make it on another occasion. Mark agreed to this, and we left to get the bus back to Sanderstead View. On the journey back to his house, Mark continued to talk about the DVD he wanted to purchase (field notes, 28<sup>th</sup> August 2014).

The written narrative within people's care plans presented the plans as owned by the people themselves. With this, the plans were presented as 'active' agents which played a role in making people's consumer and other preferences tangibly understood. However, despite being presented in these ways, during my fieldwork I did not observe any people with learning disabilities use or refer to their individual care plan. Even though they were written in the first person, it appeared to me that they were written by support workers and other staff. I also observed how care plans appeared to aid support workers and other staff members in keeping the running order of the day within their services. Similar observations were made elsewhere, at Chatsview Road, which was a residential care property and was another core fieldwork site. Here, care plans were kept in the kitchen area and mainly used by agency staff, usually those called in at the last minute to cover staff absences. Some of these people had not previously worked at Chatsview Road, and they would use care plans as a way of learning information about people they were supporting, particularly certain triggers that could cause anxiety.

In returning to Sanderstead View, I also saw how care plans were used by support workers and other staff to keep records of how much money the people they were supporting were spending. For example, the sentence within Mark's

plan that points out his awareness of needing support with spending appeared to me to be a decision that was made by his support staff. In this sense, this could be seen as countering the policy expectation that using care plans to tangibly document people's preferences would enable people to become decision-making consumers of the support they receive (Care Act, 2014). This is not to say, however, that the way support workers and other staff used Mark's plan to record his spending was wrong. Given that, as I have stated above, Mark regularly wanted to do or purchase things, it is fair to assume that his support staff needed to make sure that his spending was being monitored and, where necessary, limited. Here, care plans enabled staff to share information as a necessary means to make sure that Mark did not spend too much money. It is worth noting too that Mark had limited funds and several high outgoings, such as £500 per month taxi fares (the cost of being taken to and from his employment training service), which may also go some way to explaining why support staff were keen to curb his spending.

### **State-led community participation**

In other areas of people's support, I also observed how policy objectives of encouraging independence and community inclusion were being implemented. This was indicated, for example, in the ways that people's support hours were calculated. Hours of support were calculated through a needs assessment, which determined how much support people required. In the context of supported living services, such as Sanderstead View, this support is delivered to people as and when they wish. This approach to support is based on the principle that people should not be cared for/supported when they do not need to be, as this creates unnecessary dependence on services, thwarting people's ability to become independent.

I described in chapter four on p.121 how Sanderstead View was known as a transitions service, which was established within the organisation with the aim of supporting young adults to make the transition from children's services, a process viewed by services as being difficult to get right (Care Act, 2014; Patton & Viner, 2007). Accordingly, the transitions service at Sanderstead View was designed to

support people to make this changeover. The eventual aim was to enable the people living there to become as independent as possible and fully involved within their local communities. The organisational thinking behind this was also that it would help people to become less reliant on their support staff. Following this, as well as being housed in Sanderstead View with other young men of a similar age, Mark was funded with 18 hours of support per week that he could use when he chose.

An example of how I observed Mark's hours of support being played out in his life was during a food shopping trip on which I had accompanied Mark, along with his housemate, Joey, and their support worker, Emily. After we had finished the shopping, Mark asked Emily if we could go for coffee and lunch. Emily refused, saying that it wouldn't be fun for us (Emily and me) to sit in a café and watch them eat and drink. Emily then explained to me that Singertree Trust had recently changed its rules in relation to staff expenses, and now expected staff to pay for food and drink whilst out with people they were supporting. The aim being that support workers did not remain the default option for people with learning disabilities to spend time with, thus encouraging people with learning disabilities to extend their social networks outside of Singertree Trust (field notes, 22<sup>nd</sup> January 2015).

Providing support in ways intended to encourage people's independence and inclusion into community life could be viewed as attempts by Singertree Trust to disentangle themselves from the paradox of state support. This being, that the provision of support can inadvertently create greater dependency on the state, especially for those, such as people with learning disabilities, who are very vulnerable and who tend to have few other support networks. Indeed, this paradox of state support had been acknowledged by the CEO of Singertree Trust when they were invited to speak on a national media outlet. The topic of discussion was the problem of loneliness amongst people with learning disabilities, and Singertree Trust's CEO asked whether provider services are, in some ways, "part of the problem", in that although the professional support they provide to people with learning disabilities may be good, it may also serve to separate people from life "just as you or I understand it". The nub of this

discussion was nicely summed up in the following lines by Singertree Trust's CEO when they described how, following the NHS and Community Care Act 1990, when people with learning disabilities began being moved from the long-stay hospitals, social care support now appears to have created another form of institutionalisation, but this time in the community:

"Some aspects of this very carefully thought out support is all too quickly becoming an end to itself, and can even become a barrier between the individual and the world into which they are trying to get. If this carefully managed support doesn't actually act as a catalyst, connecting people to other non-paid people in the community, are we not creating another form of dependence? ... These challenges are leading me to completely rethink the priorities I have. I am convinced that we need to respond to the deep cries within people for personal relationships. We have to find ways to enable people to genuinely connect to others in their community" (A Lonely Society, 2016).

Singertree Trust's CEO went on to say that both the social care sector and society at large need to begin to play their parts in genuinely befriending people with learning disabilities who live in their communities. It is interesting to think about this in relation to the approaches taken at Singertree Trust, of limiting hours of support and removing staff expenses. Although an argument could be put that these organisational changes were simply attempts to reduce costs; indeed, economic pressures will always have some degree of impact in terms of what services are financially able to provide. Yet, it may also be worth thinking about this in relation to what was described across chapter two, about learning disability policy being shaped by a range of demands, and the notion of autonomy as a central goal of this. In this sense, Singertree Trust CEO's descriptions above could be reflective of these demands in relation to enabling people with learning disabilities to live without unnecessary and limiting constraints on their lives.

Despite these intentions, however, I observed how the approaches used to enable people to integrate with others outside of their formal support networks were often unrealistic. This was the case even for the people I spent time with

who were considered to be highly able. For instance, though Sam and Joey were permitted to leave their home alone, and held more financial independence than Mark, the social activities they engaged in tended to be ones organised by learning disability services. Furthermore, on occasions when they were out alone, I observed how there could be problems regarding their safety. These problems and the incidents relating to them are discussed in detail in chapter six.

I also observed how Mark was negatively impacted by aspects of the organisational rules at Singertree Trust. The staff at Sanderstead View told me that Mark was less able than both Sam and Joey, and he could not leave his home unaccompanied, as alone he would become anxious and afraid. Mark could be viewed as an example of one of the people described by Singertree Trust's CEO above. He did not have a social network outside of his professional support or family, and because of this he was fully reliant on these networks, being most reliant on his professional network for support to access the community. Furthermore, the CEO's argument that people with learning disabilities have a deep desire for personal relationships was also true for Mark, who often expressed a desire to form relationships with others, for example, as the quote at the beginning of this chapter shows, Mark wanted to find a girlfriend.

Providing Mark with a minimum set of support hours did reduce the amount of one-to-one time that his support staff were able to spend with him. However, this did not better enable Mark to widen his social network. On the contrary, this affected Mark negatively. He was unable to leave his home unaccompanied and weekly allocated one-to-one hours were too limited to allow support workers to accompany him to all the places of leisure that he wanted to go. I frequently witnessed how this appeared to be a source of much frustration for both Mark and his support workers, because, as I have stated above, he would regularly ask to be taken places, but staff would refuse because he did not have enough allocated support hours. It could be suggested here that, as his frustrations grew, paradoxically, Mark became more demanding and ultimately more dependent on his support staff.

The regular times that support workers were authorised to go out with Mark, such as during food shopping trips, then seemed to become opportunities for him to transform into leisure activities with support workers. For instance, when he asked Emily to go for coffee and lunch. It could be argued that these trips had provided Mark with an opportunity to spend time with others in places that were safe and familiar to him. Following the organisational rule changes regarding staff expenses, however, this was no longer something his support worker, Emily, was prepared to do.

Emily's decision not to have lunch with Mark may appear from the outside as unfair. The suggestion could be put that she could have agreed to go with him and not had food or drink. Yet, rather than point individual blame at a support worker here, what is perhaps more important to consider is how abstract rules governing staff expenses impacted upon everyday life between Emily and Mark. Most notably, this was evident in the ways that changes to staff expenses had altered her own expectations about her role as a support worker. Emily's refusal to accompany Mark to lunch could be indicative of how formal notions of support work, as presented through policy, were shaping her conceptions about whether her job extended to engaging socially with the people she supported. Paradoxically, Mark's ability to engage with others, and to fill his need for personal relations, was made less possible as those individuals best placed to have provided some form of this – his support workers – were organisationally prohibited from doing so.

### **Non-state-led community participation**

As well as being a central policy goal for state-run provider organisations, community participation was also a driving force within the independent advocacy group, Hear Us, that I spent time with. As I described in chapter four on p.128, although Hear Us had supported the I.T.C members in establishing their organisation, from the outset it had been agreed that once everything was up and running the advocates, Jo Parry and Sheila Biggins, would hand over full responsibility to the I.T.C members. During one social evening, a trip to the local spa, I asked Pam, one of the I.T.C members, whose decision it had been for the



I.T.C to take over the running of the group. Pam told me that Jo and Sheila had suggested it to the group, but it had always been the group's choice to do this (field notes, 17<sup>th</sup> September 2014).

At one I.T.C meeting I attended, a learning disability senior commissioner and police constable, both working for the area, were invited to discuss various initiatives the I.T.C were supporting to develop for people with learning disabilities locally. For instance, the establishment of 'safe spaces' – places within the community, such as shops and cafés, that were designated safe places for people with learning disabilities to go if they were/felt in danger (field notes, 1<sup>st</sup> October 2014).

During another of their meetings I attended, advocates Jo and Sheila were speaking with the I.T.C members about the importance of their legal rights, which they could exercise through the Mental Capacity Act 2005 legislation (MCA). Jo described to the members how it was necessary for them to have knowledge of this legislation as it would aid them in avoiding being overly and unnecessarily controlled by others, including the organisations supporting them. Indeed, Jo explicitly voiced her concerns about how, although services described themselves as using a rights-based approach to support, this was not always being exercised in practice. To illustrate her point, Jo described how services would incorrectly use the processes of 'best interests' in the MCA to make decisions on people's behalf and without consulting them. Jo then asked the members to discuss this in relation to visits to their GPs, asking whether anyone had experienced a situation when their GP spoke to their support worker rather than directly to them. One man then put up his hand saying that "I know my doctor" and then explained how during a consultation "the doctor told me to be strong and not to cry", which he said had made him feel better (field notes, 6<sup>th</sup> July 2014).

Elsewhere, the I.T.C were also supported by Hear Us advocates to organise various community events, and I attended some of these, for example, a 'Café Evening', which was hosted at Station Park Café one evening every month. Here, people with learning disabilities were supported by Hear Us advocates and the

café staff to prepare a three-course meal for up to 60 paying guests who could purchase tickets for £15. During my time spent with Hear Us and the I.T.C members, I attended one of their 'Café Evening' events. As the event consisted of serving dinner for up to 60 guests, Jo requested that the kitchen staff arrived earlier in the day to begin preparations. Here, I helped to support a woman with learning disabilities called Maggie. Upon my arrival, I was briefed by Jo not to do "anything for them, because they can do it themselves". However, whilst I was supporting Maggie in her job of preparing part of the pudding, Jo was concerned that we were working too slowly. Eventually she came to take over the completion of this task. Throughout the day, I also observed how Maggie was keen to socialise with the other people in the kitchen who were also preparing food.

Whilst at the 'Café Evening', I met a young woman in her early 20s called Geordie. During the day, when I had been supporting Maggie with her work, I had initially mistaken Geordie for a support worker or a Hear Us advocate, as her learning disability was not obvious to me from her appearance. Later during the meal, I sat next to Geordie. She told me that she lived on her own and received a small amount of support from support workers who she said she disliked and wished they would leave her alone. She then asked me what a "retard" meant as she had recently been called this by some people. Geordie also told me about her boyfriend, whom she said did not have a learning disability and who she had first met at a bus stop one evening when she was drunk. She said that, after the 'Café Evening', she was planning to go to his house and asked me if I thought it would be safe for her to travel there alone. As the evening drew to a close, one of the Hear Us advocates began asking whether any people with learning disabilities required a lift home. Geordie replied that she did not as she was going to see her boyfriend, to which the advocate agreed with no further questions (field notes, 8<sup>th</sup> October 2014).

The extracts presented above illustrate the complexities of attempting to empower people with learning disabilities to independently access their communities. The Hear Us advocate Jo's attempt to educate people about their legal rights under the MCA was logical because being better informed could mean that people would be less likely to be exploited or abused. Jo saw this as

crucial because it enabled people with learning disabilities to take control of decision-making in their lives. However, the man at the meeting who responded to Jo appeared to interpret the question as being related to his personal feelings about being comforted by his doctor, rather than about how the MCA had empowered him to take control of his life. This is perhaps indicative of how feeling emotionally supported by those around them was more important to people with learning disabilities than was the MCA legislation.

Whilst spending time with Hear Us and the I.T.C members, I observed how although the I.T.C members often appeared to be engaged in much of what Jo and Sheila were doing, the organisation continued to be run by the Hear Us advocates. During my visit to the 'Café Evening', as well as other events the organisation ran, I observed too how these were being headed by Jo and the other advocates, who would do most of the work. Further to this, the arrangement at the 'Café Evening' appeared to be overly ambitious in that there was not enough time to engage people with learning disabilities to carry out tasks themselves, whilst also producing a three-course meal for paying customers. As a result, I observed how Jo was continuously stepping in to take over tasks so that they could be completed at a faster rate than the people with learning disabilities were able to achieve. From these observations, it did not appear that the ways people with learning disabilities were being expected to engage with their communities was, or indeed could ever, be realised.

In addition to observing the aims of the I.T.C, however, the incident I experienced with the young woman, Geordie, illustrated the potential risks that people with learning disabilities can be exposed to when they are alone in the community. After speaking with Geordie during the meal, I felt her to be a vulnerable person and so was uneasy about her decision to meet her boyfriend. I had wanted to suggest to her that she travel home with an advocate, but I also felt uneasy about suggesting this – I did not know Geordie, and was aware that the Hear Us advocates did know her. I did not want to overstep the line and make possibly inaccurate assumptions about her inability to travel alone. On a broader level, this situation indicated to me the difficulties involved in making decisions about

how much and how little freedom people with learning disabilities should be given, including the consequences of either giving too much or not enough.

### **College courses**

In other areas of social care support, I observed that several people with learning disabilities I spent time with were taking part in formal education through college courses. As a service provider, Singertree Trust was partnered with other services in the local area such as local colleges to provide opportunities for people they supported into formal education. However, these were not without controversy and I observed how staff within Singertree Trust expressed differing concerns about the people they supported engaging in educational college courses.

Singertree Trust had set up a small department of job coaches who were dedicated to supporting people into paid employment outside of their support service. During a meeting I attended with the job coaches, college courses were discussed as being part of the reason the job coaches had been experiencing difficulties in supporting people with learning disabilities to gain paid employment in the community. The reason being that local authorities were habitually allocating people funding for college courses without thinking about other activities that could be commissioned. As a result of this, the job coaches said that college courses, along with leisure activities, tended to be the only options that social workers would inform parents about. The job coaches found this to be problematic because once the person had completed their course, they did not receive any further support to use their acquired skills in practice, for instance, through employment. Given this, the job coaches wanted local authority commissioners to gear their funding towards paid employment, rather than college courses and leisure activities (field notes, 11<sup>th</sup> March 2015).

At Chatsview Road, the residential care home which was one of my core fieldwork sites, the house manager, Rachael Patrick, talked about a number of difficulties she experienced with college placements. She described how it was often not possible to secure college placements for the people living at Chatsview Road

because they were considered by the local authority to be too old to benefit from formal education. Rachael said that this was problematic because, in accordance with policy aims of promoting training and employment, most of local authority funding for day placements was being resourced into formal education and employment training. Conversely, she said this meant that funding was being removed from day centre services. Rachael felt that this had a negative impact on some of the older people living at Chatsview Road, who had been attending their day centres for many years, and which were now being phased out only to be replaced with other placements not considered to be suitable for older individuals. Rachael spoke of how she found this very concerning because not attending daytime activities outside of their home meant that people were staying inside for long periods, which could be frustrating for them.

In addition to the older individuals, a young woman, Rebecca Smith, in her early 30s, also lived at Chatsview Road. Rebecca was one of my core participants. Rachael told me how Rebecca would have normally been viewed as too old to receive funding for formal education, however, Rebecca was fortunate in that the local authority were satisfied that she was benefiting from college. Rebecca had been placed at Chatsview Road following an extremely traumatic incident she had experienced some years before. The incident, which had resulted in several years of acute mental ill health and a diagnosis of post-traumatic stress disorder (PTSD), had taken place in her country of birth, and had precipitated her and her family's move to the UK in the 2000s to seek medical treatment (including inpatient treatment under the Mental Health Act 1983). Following her discharge from hospital, it was agreed that Rebecca remain under supervised support and so it was decided that she be moved to Chatsview Road. She experienced selective mutism, which I was told had started at some point after her trauma. She usually communicated using signs and pointing, though staff informed me that she still retained the ability to speak, and on occasions spoke with them. On my final day of fieldwork Rebecca spoke with me when I was saying goodbye to her.

When I was first introduced to Rebecca, her house Manager, Rachael, described her as "doing well". However, one day when I was spending time with Rebecca

whilst she was out bowling as part of her placement with a community learning disability team, one of the support workers in the team told me that he thought I should know that Rebecca possibly had schizophrenia and that her behaviour could be very erratic, often transitioning between tears and hysterical laughter. He said that when she had been in an inpatient unit she had required 3-to-1 support. He also said that he was angry that no one had told me about this, and that he felt that Rebecca was receiving support in the wrong type of living environment. As my fieldwork at Chatsview Road continued, I began hearing different things about Rebecca. A support worker told me one day that, because she was becoming increasingly violent to others in the house, they were going to invite a police constable to come to speak to her to try to make her aware of the severity of her actions towards others.

Given that Rebecca rarely spoke, it was difficult to determine her perspective. However, I observed how she sometimes appeared to be frustrated with the support she was receiving. Indeed, there were times when I was spending time with Rebecca that I sensed discomfort and frustration on her part. For example, I observed on one occasion I was with Rebecca and one of her support workers when she suddenly became very emotional and began to cry. Her support worker later told me that Rebecca could become upset if people were talking around her and she was not involved in the conversation. Another time, after I had been bowling with Rebecca, a support worker was driving us back to her home and I observed how she appeared to be very tense, as she was tightly clenching her fists.

Elsewhere, one of the college courses Rebecca attended, 'Becoming Independent', did not appear to me to be appropriate for her intellect. During my fieldwork, I accompanied Rebecca to this college course which took place weekly at a local community college. The course was two years in the first instance, which could then be continued with a one-year course if appropriate. The field note excerpts below relay my experiences of the day spent with Rebecca, her college peers and course teachers:

The morning session of the class consisted of Hilary [the class teacher] teaching people different times on the clock face – for example, quarter past, half past and three quarters past the hour – with the aim of helping them to better manage time when/if they move into the workplace ... In the session before lunch, the class were then asked to choose topics relating to health and safety in the workplace, for example exit signs, which they would then produce a project for and present the findings to the rest of the class after half term. Hilary went around the group asking each person which topic they would like to focus on. When she got to Rebecca, Hilary suggested to her that she do fire safety (field notes, 13<sup>th</sup> October 2014).

Based on my knowledge of Rebecca, I was not sure what benefit this course would bring her. It appeared that she was being moved through the processes of learning disability support in a generic rather than personalised way. Yet, it is also important to acknowledge that Rebecca's circumstances were exceptional in that there appeared to be no support that could meet her particular needs. She had a very mild learning disability, but in some ways she appeared to be vulnerable and to require the kinds of support that were provided to the other people living at Chatsview Road. In this sense, her situation indicated the kinds of immense challenges that social care services are faced with, in terms of supporting people with such complex lives. Although Rebecca's freedom was in some ways being constrained, her situation shows the difficult decisions – and with them sacrifices – that sometimes need to be made to keep a vulnerable person safe.

I remained with Rebecca and her class into their afternoon session, for which a different activity from the morning's one had been planned, and which the following field note excerpt describes:

Then at break we all went down to the canteen for snacks and drinks. Paul and Stuart [two members of the class] arrived at the canteen late because they are wheelchair users and had problems accessing the lift. With the assistance of a support worker, named Samantha, who had been assisting Hilary with the class, Stuart bought a pie from the

canteen. All the other students were also eating and drinking – either what they had bought from the canteen, or their own homemade packed-lunches, but because the others had arrived earlier than Stuart they had all nearly finished their meals by the time he began his. Whilst Stuart was still eating, Samantha told the group that the class's afternoon session needed to begin and so they would have to go ahead without Stuart.

The afternoon session was to take place in the canteen area. This session involved practical work where the group took on roles in a recycling company. This company – which involved members of the class collecting rubbish and recycling materials in the canteen – was set up by Hilary with the aim of providing the students with workplace skills. The students had been designated different roles: manager, floor manager, union representative, and general employees. Stuart, who had now joined the group, was taking on the role as manager, and so he began to oversee the other students in their roles as general employees, who had already begun picking up litter and recycling from the canteen tables. After they had collected most of the rubbish and recycling, the general employees didn't appear to know what to do and so I suggested that they ask their manager (Stuart). When they asked Stuart, he decided that he would help them in the task, and so started to take a bag of rubbish over to one of the bins in the canteen.

Before starting to dispose of the rubbish items Stuart began attempting to put on some plastic gloves, but his hands were shaky and he couldn't gain purchase on the thin plastic. While this was happening the support worker, Samantha, who had been overseeing the students' actions, came over to the group and told them that as a manager it was Stuart's role to delegate tasks to his employees. What's more, she said, it was clear that he wasn't capable of doing the task at hand and so should be telling his staff members to do it. She then went on to say that Stuart taking over the roles of his staff gave them cause to dispute this with their union rep. At this point, Stuart



stopped trying to put on the gloves, instead he tried to hide them by screwing them inside his hands. He then moved away from where the group were standing. I was also standing a little way back from the group, and as he moved out he looked over towards me and said he couldn't put on the gloves because they were sticky. The rest of the group then disposed of the rubbish and recycling without Stuart's help (field notes, 13<sup>th</sup> October 2014).

It is possible that these extracts indicate bad teaching on the part of Hilary and Samantha, in the sense that they were not able to interpret and deliver their independence course in ways that were beneficial to the students. Yet, these failings also need to be understood in the context of a service where there are reduced teaching resources and training to deliver support to complex groups of people (Efthymiou & Kington, 2017). Additionally, I think this example serves to highlight how some of the services being provided to people with learning disabilities, which are so overwhelmingly focused on promoting empowerment in individualistic ways, can be so far removed from their actual needs and experiences. The aspiration of employment factors hugely in terms of promoting what should be available to people with learning disabilities, as well as what they themselves should be aiming for. Importantly, however, the statistics on numbers of people with learning disabilities in employment tell a different story. For instance, in England during 2015-16, of all the adults with learning disabilities known to services, 6.0% were reported as being in paid employment. Furthermore, 69.3% of these jobs consisted of fewer than 16 working hours per week (Public Health England, 2016).

As I have stated, these figures refer only to people who are known to their local authority services, who represent a minority of people with a learning disability in England and who are mostly made up of people with more severe learning disabilities. The data on numbers of all adults with learning disabilities in England in paid employment remain scant, however, previous research has estimated that around 17% of all working age people with a learning disability have a paid job (Emerson and Hatton, 2008). Crucially, this sits in stark contrast to the general population, in which 74% of people in England aged 16 to 64 are in full time paid

employment, working an average of 37.5 hours per week (Office for National Statistics, 2016). As was described in chapter two on pp.56-57, the limited numbers of people in work, as well as the limited hours of work that are available to them, is revealing of how employment as a means of becoming independent from the state is often economically unviable for many people with learning disabilities (Redley, 2009).

### **Paid employment and employment training services**

In addition to supporting people to develop employment-based skills through formal education, Singertree Trust also supported people with this through employment training placements. Similarly to the college course described above, employment training services were community-based organisations that Singertree trust had partnered with in order to provide opportunities for the people they were supporting. However, Singertree Trust itself had also established some in-house employment training services, which were part of their aim to develop services to support people into employment. The services themselves tended to be designed with a view to replicating, as much as possible, real-life working environments. For instance, aspects such as punctuality and work ethos were concentrated on by support workers and managers.

During my fieldwork, a number of staff at Singertree Trust explained to me how the aim of employment training services had originally been to provide people with safe environments in which to develop workplace skills. However, unintentionally, these services had too often become permanent support services for people, just like any other day placement. Given this, they were both expensive to run and there were concerns that they were stagnating people's ability to access their communities in independent ways. In recognising this, Singertree Trust was attempting to develop strategies to encourage people to move on from employment training services. This was reflected, for example, in the small department of job coaches that had been established to support people into paid employment outside of their support service.

I have already described on p.143 how I attended one of the job coaches' meetings where they discussed how local authorities were commissioning funding for college courses rather than support into paid employment. During this meeting, the job coaches also discussed how they could develop approaches to encourage people with learning disabilities at employment training services to attend job club sessions, which were aimed to support them to develop skills to move into paid employment. However, there was a problem with this approach as people were not attending these sessions. The job coaches described how this was despite their identifying that certain people using two of their employment training services, Pigtree Farm and Bristlehedge, were "employment ready", meaning that they should have been moving into paid employment outside of the organisation. One of the job coaches suggested that it might be an encouragement for people if they made job club into "a bit of a course, and give them a certificate at the end" (field notes, 11<sup>th</sup> March 2015).

Despite the problems that were voiced by Singertree Trust job coaches about employment training services, whilst conducting my fieldwork they were still being widely used by the organisation. These services included activities such as farming/gardening and arts and crafts, and I spent time with people at both these types of services. However, as I described in chapter four on pp.125-126, three of my core participants regularly attended farms, and so a great deal of my fieldwork was spent in this type of service. Mark and Joey, the two young men living at the supported living property, Sanderstead View, attended Pigtree Farm several days a week. Mark had been attending this service for several years, but Joey only began attending with Mark soon after he moved into Sanderstead View.

When starting work at the farm, Joey joined Mark in the farm's nursery, an area mainly designated to potting and planting. Here, I observed how Mark and Joey tended to approach their work at the farm in differing ways. From the outset, Joey regularly kept himself busy and often appeared keen, asking support workers if he could take on jobs, which usually involved asking to use the electric lawn mower and heavy manual tools. Very early on, his attitude and approach towards his work was noted by Jane, one of his support workers, who told me that, because of his abilities, Joey would soon be moved out of the nursery and into

other areas of the farm. Work on the nursery was viewed as simpler work than other areas of the farm, such as landscape gardening, which involved the use of large lawn mowers and could only be carried out by the most able, usually young men. I described in chapter four on p.126 how there were opportunities at Pigtree Farm to move into paid landscaping work. Very soon after he first started working in the nursery, Joey requested to Jane and his other support worker, Samantha, to be moved onto landscape gardening work.

Unlike their impression of Joey, the support workers at Pigtree Farm would sometimes describe Mark as “lazy”. Quite often Mark would tell either myself or his support workers that he did not feel well and needed to go home because of pains he was feeling in his stomach. His support workers told me that this was his way of trying to get out of doing work and that his lack of motivation to engage in the work had previously resulted in him being sent home by staff because he was not doing his job properly. Despite this, however, I observed how Mark could become engaged when he found something at the farm that he really enjoyed doing. For example, occasions when he chopped up wood or branches from trees, which appeared to ignite energy within him and he would become excited, taking on a managerial role and instructing everyone else what to do. However, his support workers were often not keen to allow Mark to chop wood or take branches from trees, as they were concerned that he would either injure himself or ruin the trees.

Another of my core participants was Ray Winder, an older man in his 70s, who lived at Chatsview Road. As the house manager, Rachael described Ray as one of the individuals at this property who was considered to be too old to benefit from formal education. Instead, Ray had been allocated a gardening placement at Goatsgruff Farm, which I described in chapter four on p.126. Along with a small group of other people with learning disabilities, Ray attended Goatsgruff Farm every morning between 10 a.m. and 1.30 p.m. All work was carried out with assistance from support workers and ranged from tending to a nearby allotment, to potting plants in the greenhouse, and making arts and crafts. Most of what was produced on this farm was sold in the on-site shop or used for ingredients in the café, which was situated opposite the farm. Rather than being viewed as a step

towards paid employment, Ray's work at Goatsgruff Farm was framed in terms of therapeutic support, with the aim of providing him with a daily purpose.

Support workers at Chatsview Road explained to me that Ray could be very "bossy" towards other people in his house, which could lead to aggressive behaviour on his part. Aware that Ray enjoyed farm work, they decided to support him to start his own vegetable patch in the garden at Chatsview Road, in the hope that this would help with his moods. This was the same vegetable patch that Ray showed me when I visited him at Chatsview Road for the first time.

Ray's experiences of employment training services indicated to me that this type of service could be empowering. His work in a therapeutic setting showed that this kind of small-scale setting, where work completed was not focused on production but rather on what he found enjoyable, could enable him to take some level of control over what he produced. For Ray, who experienced difficulties in managing his emotions, this was clearly an important contributory element to his wellbeing. Similarly, Joey's experiences of working at Pigtree Farm could be described as positive in that he was able to move into paid employment here, as well as doing work that he found to be personally satisfying. It could be viewed as concerning then that, under current policy objectives, consideration was being given to phase out these types of services at Singertree Trust. It is true that they may not have been encouraging individuals to progress into paid employment outside of the organisation, however, Joey and Ray's experiences show that these kinds of services were safe spaces that provided opportunities for people to thrive in other ways.

For Mark, however, work experience was quite different, as it did not seem that he was regularly able to feel a sense of control over what he was doing. From my experience of working with Mark, it did appear to be difficult to motivate him to do his allocated tasks. In this sense, his perceived laziness by support workers was arguably an understandable source of frustration for these staff members who were trying to engage Mark in the farm work. Indeed, the fact that he would only show interest when the work excited him would have no doubt not gone down well with support workers who, in their roles, were probably all too aware that the

'real' world of work also involved learning that we must do things that we do not always find rewarding. Yet, it might be worth pointing out that, on top of not being able to take control of his work, Mark did not get paid for his time at the farm. Although Mark may not have been explicitly aware of these exact forces, all this could have contributed him not feeling motivated to take part in the farm work. Given Mark's circumstances, is it perhaps also unrealistic to suggest that he should have been expected to acknowledge that some work is not enjoyable but must be done as part of our social responsibility.

### **Economic value versus human value**

During my fieldwork, I spent time in a service outside of Singertree Trust that also focused on employment roles for people with learning disabilities. I have already mentioned on pp.140-143 that the social enterprise group, I.T.C, who were supported by the Hear Us advocacy group, held their 'Café Evening' event at Station Park Café. This café provided voluntary employment opportunities for different groups of people, including people with learning disabilities. During a formal interview with Steve Connors, who ran the café, he described to me how, for a few years, the café had done its best to make sure it included adults with learning disabilities in meaningful ways, and he described the challenges of making this happen:

“Originally, that sometimes took the form of purely providing space, and sometimes we had so many adults with learning disabilities that they weren't really meaningfully occupied, and it felt like they were just being parked here to keep them safe during the day. About five years ago, we changed the format of the café slightly, and at the same time we made a decision that we would do all we could to ensure we would include adults with learning disabilities, but that they were here for a meaningful purpose. And as a result, we have at least one, usually two adults at any one time, helping us with clearing tables, taking out orders and other front of house duties ... They get, I believe, in return, they get value and pride that they are giving a service, and they also get a rhythm of life.”

In relation to the problem of including people with learning disabilities in employment in meaningful ways, Steve pointed out that the rationale at his café was very different to a conventional paid employment setting. At the café, value was not just about production, but also about sharing tasks to give value to others:

“It works here because our aim is to be a supportive, welcoming environment ... when employment is competitive and is about producing things, it can be very hard for someone with learning difficulties to compete with that.”

Steve gave an example of a man working at the café who was deaf, blind and a wheelchair user, explaining how ensuring that this man made a valuable contribution involved understanding what he could contribute in this context. Steve described that this was about the importance of finding ways to ensure “we are giving people value”, which was about having a set up with a range of things that people could do, and in ways that allowed them to see how what they did contributed to making things succeed. Importantly, he said, people with learning disabilities needed extra support to work out their role, what they were good at and how they could contribute (interview, Steve Connors, 12<sup>th</sup> September 2014).

Steve’s descriptions here nicely draw out the contrast between the kinds of sheltered work as therapy that was taking place in his café and ‘real’ work as work. As such, this indicates the differences between work that measures value through economic productivity and work that measures value through people’s individual contributions to the whole. For Steve, when working with people with learning disabilities, it was the latter type of work that was of focus, because this allowed people to feel that, however small their contribution, they were genuinely part of something. This feeling, he said, was crucial as it was this that provided people with a sense of self-worth. In this sense, the voluntary work that Steve was promoting at Station Park Café could be seen as similar to Ray’s experience at Goatsgruff Farm, as both were about acknowledging the intrinsic human value of each person by finding what they were able to do to contribute in genuine ways. In this sense, instead of work-value being created through economic production, it promotes the notion that the value is derived from the act of contributing itself.

As I have already described, the management at Singertree Trust wanted to engage people with learning disabilities into paid employment outside of their organisation. Indeed, they viewed supporting people into paid employment in the in the community as a way of enabling them to break free from the restrictions and institutionalising effects of employment training services. Essentially, the aim here was to try to provide people with access to what was considered to be a 'normal' life. As has been outlined in chapter two on pp.55-58, the drive within policy towards promoting employment for people with learning disabilities is similarly bound up in the notion of work being a positive part of human life. These objectives are echoed in Singertree Trust's own documents:

'Having a paid job should therefore be seen as the default outcome for young people with a learning disability, just as it is for their non-disabled peers. It isn't just about financial independence, but also social independence, learning new skills, meeting and interacting with people of different ages and backgrounds, being part of a local community, having a valued social role, improved mental well-being, increased physical activity, increased confidence, independent travel skills, gaining a sense of responsibility, being accountable to someone other than your parents, feeling pride in one's work, stepping towards the future, and not being bored - the list goes on' (reference not provided for anonymity purposes).

There are strong similarities in Singertree Trust's descriptions of their aims of employment with the kind of value-making that Steve described he was trying to achieve at his café. Problematically, however, when these ideas about value were translated into practice at Singertree Trust, rather than the focus being about the act of contributing in and of itself, huge importance was being placed upon whether the people were seen to be replicating 'normal' employment behaviours, *i.e.* working in autonomous, self-sufficient and productive ways. For instance, rather than recognising some of the positive experiences that Pigtree Farm could offer to people like Joey, the view was taken by the senior job coaches at Singertree Trust that this type of service stagnated people's ability to take on 'real' work in the community. The reality was, however, that people like



Joey were most probably thriving under the conditions at Pigtree Farm because they were sheltered from the demands and expectations of a 'real' working environment.

Importantly, focusing on a notion of 'real' work was perhaps most damaging for the people who experienced difficulty in functioning under any kind of employment conditions, even the more sheltered employment settings, such as the farms, the church café and the college courses described earlier in this chapter. Here, the downside of normalisation was made evident as unlike individuals such as Joey, who were productive enough, other individuals, such as Mark and Rebecca's fellow college students, had few other options in the sense that, the services that had been established to meet their needs were essentially ignoring those needs on the grounds that they should be more able. The result here was that any potential people may have had to thrive was being thwarted by the unrealistic expectations being laden upon them.

## **Chapter conclusion**

In this chapter, I have explored how people with learning disabilities experienced policy objectives in the context of their everyday support. Through the ethnographic findings, I have shown how people with learning disabilities and their support staff held differing expectations about their relationships. Overall, the support provided to people tended to adopt the current policy objectives of encouraging them to become independent and a part of their communities on equal terms with their non-disabled counterparts in quite self-sufficient ways. These objectives also appeared to be wrapped up in the various constructed identities of people with learning disabilities, as described in the previous chapters. However, people with learning disabilities were often unable to achieve the levels of autonomy that were being expected of them through these constructed identities. Conversely, however, although they did express an awareness of and desire to be empowered, they appeared to express different understandings of this. In particular, these desires appeared to be bound up in their complex relations with the people supporting them, and so in this sense, could not be viewed as autonomous and self-sufficient.

In the everyday context of support, these conflicting expectations between people with learning disabilities and their support staff created tensions and conflicts. Moreover, these issues also brought to the fore the complexities, as well as possible risks, of promoting independent living and community inclusion for people with learning disabilities. In doing so, perhaps this also raises the question of whether ways of supporting independence for people with learning disabilities might be better achieved through the more protected environments, such as Pigtree and Goatsgruff farms, as well as the independently run community projects, such as Station Park Café. Despite the concern that these settings were considered to prevent people from accessing the community in the same way as everyone else, they did allow people with learning disabilities to gain experiences in safe environments. In the next empirical chapter, I will explore these themes further by focusing on how support workers and other staff members experienced policy objectives and how these experiences were played out in the minutia of everyday relations in these settings.

## Chapter six

### How support workers and other staff experienced the implementation of government policy objectives

#### Introduction

In this chapter, I present the ethnographic findings that detail how support workers and other staff members experienced policy objectives aimed at empowering people with learning disabilities. Through this, I show how these policies placed conflicting demands upon support workers. On the one hand, they were instructed to fulfil policy objectives pertaining to empowering people with particular kinds of independence and community inclusion. Whilst on the other hand, they were faced head-on with the vulnerabilities and human needs of the people they were supporting. In the context of everyday support, these conflicting expectations placed on support workers emerged as points of tension and conflict between them and the people they supported. Within chapter five, I also touched on how these issues served to illustrate the complexities and possible risks involved in promoting independent living for people with learning disabilities. Along with other tensions and conflicts, I will explore these issues further through the following themes of moving from day services to employment training services; cultural changes in social care: moving from the institution to supported living; domestic responsibilities; personal physical contact; people with learning disabilities getting into trouble; and policy expectations of responsibility versus the reality of lived experiences.

*“When something is going wrong, you would really really like at that moment for that person never to go out on their own because they’re safe, and you know you haven’t got to sit in a strategy meeting. But, when it’s all going well, of course it’s the right thing to do. It’s a difficult one. We don’t get paid a lot of money, at the end of the day, for the*

*responsibility we have to take ... and what could happen if things did go wrong*" (interview, Nigel Sutton, locality manager, 2<sup>nd</sup> April 2015).

### **Moving from day services to employment training services**

Chapter five ended with a discussion of how people with learning disabilities experienced differing types of employment. The ethnographic findings in this chapter reflected current policy aspirations towards making employment a central goal for as many people with learning disabilities as possible. These findings also showed the complexities of realising these aspirations for people with learning disabilities. In the job coaches meeting I attended at Singertree Trust, which I have already described in chapter five on p.143, the job coaches discussed how they felt the reason why so few people with learning disabilities were in paid employment was because of a lack of both funding and will on the part of the local authority. Though they said that there were employment initiatives taking place "here and there", when local areas had managed to secure funding from their local authority, the job coaches felt that there remained a backwards approach and lack of employment strategy by local authorities. The job coaches viewed this situation as indicative of the implementation barriers which inhibited people with learning disabilities from accessing employment in the community (field notes, 11<sup>th</sup> March 2015).

During this meeting, one of the job coaches who was supporting nine individuals to find paid employment relayed that she still hadn't been able to find anyone work. Following the end of the meeting, I spoke with this job coach about searching for work for people with learning disabilities and she told me that her biggest barrier to this was finding work for people that they were able enough to do. She said she had tried and tried, but couldn't find anything for them with their skill sets (field notes, 11<sup>th</sup> March 2015).

Within other services at Singertree Trust, I also observed the move towards support that promoted paid employment. The service at Bristlehedge had historically been a day centre service, however, the managers here were attempting to transform it into an employment training service. This transition

represented the policy stance that I have described in chapter one on p.41 that day centres are now generally considered to be 'institutional' and 'have made a limited contribution to promoting social inclusion or independence for people with learning disabilities' (Department of Health, 2001: p.76, para.7.21). The managers at Bristlehedge expressed their awareness of this, and in response, were trying to evolve their voluntary-based work, including arts and crafts and packing medical boxes for the NHS, into employment training and paid work activities. One support worker, Frank, who supported people to pack the NHS medical boxes, told me that they were not endorsing sweat shop or slave labour conditions, but rather were trying to "create a realistic working environment" (field notes, 22<sup>nd</sup> August 2014). With regard to the medical NHS box packing, the locality manager at Bristlehedge, Hannah Stokes, explained to me how she had fought hard to set up a formal contract between Bristlehedge and the NHS, which had allowed people doing this work to be formally employed and paid at the minimum wage (field notes, 25<sup>th</sup> July 2014).

Despite the changes that Hannah Stokes at Bristlehedge had pushed through in terms of employment opportunities for the people she was supporting, during my visits to Bristlehedge several staff told me that they felt the future of their service remained uncertain. The support worker, Frank, mentioned above, described how their contract with the NHS was in jeopardy because now people were getting paid, the NHS were requesting higher turnovers of completed boxes. He described how he would try to support people as much as possible to generate more completed boxes, often compiling many boxes himself. Yet, unfortunately, this was not sustainable over the long term, and there were concerns that the NHS were considering contracting this work elsewhere. When I spent time with Frank and the people he supported packing the NHS boxes, I did observe how some people did not appear to be engaged in their work. This was particularly so for a young woman, who was much younger than most of her colleagues. However, Frank told me that, for the people who had been attending Bristlehedge for many years, who were mostly older individuals, the changes to their employment status – into formal employment and receiving the minimum wage – were irrelevant, as they enjoyed the work in and of itself and would have been happy to continue doing it unpaid (field notes, 22<sup>nd</sup> August 2014).

Whilst I was at Bristlehedge, Hannah invited me to visit several other places in the local area that she managed and where she had helped to secure part-time and occasional employment for people with learning disabilities. These included one small café and another larger café that was part of a small farm, which had been set up as a social enterprise in collaboration with a local residents' association. Hannah described the social enterprise as the type of service that was one of the only ways forward in a time of social care funding cuts. She described how this was "about thinking creatively" (field notes, 25<sup>th</sup> July 2014).

Despite the enthusiasm shown by individuals working at Singertree Trust towards engaging people with learning disabilities into paid employment, there were some complexities in making this happen. For instance, the job coaches at the meeting described above spoke of how a lack of resources and impetus from local authorities were the reasons for a lack of employment opportunities for people with learning disabilities. However, if indeed lack of resources and impetus were reasons for a lack of available employment, they may not have been the only reasons. For example, as the experiences of the job coach who was tasked with supporting people to find work in the community indicated when she described how she was finding it difficult to select employment roles that met people's skillsets.

At Bristlehedge, the image provided to the observer of people with learning disabilities taking part in unpaid production line tasks in a day centre is arguably not indicative of a vision of independence and community inclusion. In this sense, the attempt by Hannah at Bristlehedge to transform this service into an employment driven one is understandable on a human level as well as a policy one. Indeed, support worker Frank appeared keen to point out to me the respectability of their service when he stated that they were not a sweat shop or engaging in slave labour. However, these concerns about becoming formally employed and receiving a wage were not voiced by the people with learning disabilities at the centre. Rather, as Frank pointed out, he felt that some of the people would have been happy to continue doing the work unpaid. Indeed, for some of the older individuals who had been attending the day centre for many years, the systematic and instrumental tasks of box packing appeared to be

enjoyable. Here, I also observed how Frank interacted with the older people he supported to pack the boxes, as he would engage with them in relaxed ways. Similarly, these individuals appeared to be quite attached to Frank, wanting to remain close to him throughout their time spent at Bristlehedge.

It was clear that through Hannah's efforts, paid employment – albeit part-time or occasional – had been made possible for some people with learning disabilities in her services. Yet, it is also an important point to make that I noted a clear distinction between the abilities of people with learning disabilities who had been employed to work in the local cafés and those of the people who were packing medical boxes for the NHS at Bristlehedge. Despite Hannah's intentions to support people with learning disabilities at Bristlehedge into paid employment, it could be argued that in attempting to comply with these aspirations, unattainable expectations were being placed on some of the less able people with learning disabilities at Bristlehedge. A move that was possibly detrimental for these people in that it jeopardised what was important to them – taking part in an activity in a place where they felt safe.

Yet, another important aspect to highlight here is that Hannah and her team did not have a choice about whether to introduce these reforms to their services. Bristlehedge was facing closure if it could not show that it was working in accordance with employment law, as well as the organisational strategy at Singertree Trust. An organisational change that was indeed evident amongst the job coaches' discussions described above. Moreover, this point was also echoed during another meeting I attended with support workers and management. The manager heading this meeting described that there was a need for Singertree Trust to expand the types of support provided. This was spoken of as moving away from "direct care", such as nursing home facilities, and towards support that took place outside of people's homes and in the community, such as employment (field notes, 11<sup>th</sup> December 2014). This could be seen as evidence of the pressures that Hannah and her team were under to fit with this vision of employment. In an effort to retain the services she was providing, and to continue supporting people who had been attending her service for many years, Hannah was attempting to comply with these conditions. However, the result of this was

that her team were being forced to place unrealistic expectations on the people they were supporting.

### **Cultural changes in social care: moving from the institution to supported living**

As well as transformations taking place in day services, elsewhere within Singertree Trust I observed how alterations had been made to accommodation services. This was in order that they complied with government objectives of ‘an ordinary life’ (Towell, 1988) and community inclusion (Department of Health, 2001), aspects which were discussed across chapters one and two. During the staff meeting I have already described above, which included support workers and managers, I observed how this change was being reflected in Singertree Trust’s organisational strategy. Here, the need to provide services in accordance with the government’s goals was described as the need to continue generating “business for the organisation”. One of the senior managers leading the meeting expressed their awareness for the need to expand the types of support provided, so as to allow the organisation to adhere to the changing market demands. In this vein, the manager pointed out that moving away from nursing homes as a model of care was driven by a dual impetus of financial as well as ideal-based objectives: “Singertree don’t want to fill beds for nursing homes because these aren’t the types of places we want to fund – they are too expensive and not within our ideology” (manager, staff meeting, 11<sup>th</sup> December 2014).

Elsewhere, during a formal interview with Sarah Hill, the operations manager at Singertree Trust and the individual who provided me access to fieldwork sites, she described this “ideology” in relation to the historical development of learning disability support. Sarah described how, at the time of the shift in models of care, she had been a support worker at Singertree Trust. When reflecting on this, she said that social care support has been entirely changed from how it was in 1983 when she was beginning her career in one of the NHS long-stay hospitals:

“When I think back when I first started ... you still had locked wards, you still had, you had the support workers and the managers that had



been around for a long time that were still very much into, you know, you do as I say, you know, when it's lunch time it's lunch time and you don't have choice, that's what you eat and it's put in front of you."

In accordance with wider changes taking place across the UK in learning disability social care at this time, Sarah described how, during the 1980s, "Thinking started changing around, you know around how you treated people with learning disabilities, and getting them to, you know, have choices." She also recalled how the treatment of people with learning disabilities, often by older staff who had been there for many years, began changing following the arrival of "the younger people coming in with new ideas and things like that." As has been highlighted in chapter one, this change in thinking around the importance of choice was an integral facilitator in propelling movements towards the eventual termination of the long-stay hospital as an institution of care.

Yet, despite great bounds being made regarding the treatment of people with learning disabilities, Sarah felt that even now in some of Singertree Trust's services the "old-style ways of caring" remained engrained in some behaviour and attitudes of staff. Sarah described how, often the only way to counter this was through a complete overhaul of the service, resulting in the service being shut down and people working and living there being relocated elsewhere. This, Sarah described, had been the case with some of their longer running community-based services:

"Cos we've still got, even within Singertree, we've still got some services with some really old staff that have still very much got the old-style of caring ... and most of the time, the only time that we find that we can change a service is when it's closed and those individuals in that service are given new opportunities, like individual flats."

In accordance with this, Sarah pointed out that one of the reasons for moving staff into new services, such as individual flats, was because the structural environments were such that "the staff team have to change". In stating this, Sarah appeared to contend that staff behaviour could be shaped by the structural

environments of support settings, which she described directly impacted on the “old-style of caring”. Sarah went on to say that this could be combated through supported living: “Yeah, so that’s why Singertree have gone down, very much down the route of supported living, erm which is a national thing as well, rather than residential care”.

Here, she was explicit that supported living directly correlated with the ability of people to make individual choices. She stated that having this freedom to choose was of such central importance that it was preferable to living with and even sharing meals with others:

“But if you’ve got those three people living in their own individual flats, they’ve got choice haven’t they. They’ve definitely got choice around what they want to buy shopping-wise. They’ve definitely got choice around who they want to support them. Whereas, in a residential care, there’s two other people that they’ve got to think about. They might not want that for lunch, but the two other people want that for lunch, or, so there’s, there’s less choice, there’s less opportunities for somebody to say, ‘I want to go out today’, because you’ve got to think about the other two people in the house ... whereas if you’re in your own individual flat, and you’ve got a set amount of one-to-one hours, then you get that choice to go out when you want to go out” (interview, Sarah Hill, 3<sup>rd</sup> April 2015).

Sarah differentiated supported living from other community-based models, such as nursing homes and residential care, stating that the latter remained a threat to people’s individuality. She located this threat as emerging mainly from the conflicting needs and wants of the multiple people living together in a single setting. Conversely, she stated, it was through individually focused supported living that an individual could do as they wished, unencumbered by the needs and wants of others around them. In this sense, it is individuality that is to be cherished over and above communality, such as living with and eating meals with others. The statement that “you’ve got a set amount of one-to-one hours, then

you get that choice to go out when you want to go out” arguably implies that Sarah viewed choices for people with learning disabilities as paramount.

It is important here not to fall too much into the trap of seeing the past through today’s eyes. It was shown in chapter one that the vision behind the institutional model of care described by Sarah was, at heart, benevolent in that there was a desire to care for and protect vulnerable people who did not have the skills to do this for themselves. However, what hindsight affords us with now is the knowledge that living on these kinds of big scales tends to lead to people’s individual needs being usurped by the overall daily running of things. Indeed, as has been discussed across both chapters one and two, historical events tell us that institutionalised settings, such as in the case of the long-stay hospitals, can all too often result in the kinds of ‘batch living’ that Erving Goffman vividly described (1961). This can encourage the processes of othering, wherein staff begin to dehumanise the people they support (Menzies, 1960). In this, Sarah’s descriptions above clearly pointed out important factors relating to the intricate relationship between care and support and the physical environment in which this takes place.

When considering Sarah’s long career in learning disability social care, in which she had experienced both institutionalisation and community living, it is perhaps easier to see why she was so confident that supported living was the vehicle with which learning disability support could move on from the past and ensure that people with learning disabilities were treated with respect and compassion. In this sense, it is also understandable why, as an organisation, Singertree Trust was keen to transform its strategy to accord with national policy. On one level, altering their services to align with current policy objectives would allow them to stay afloat as a business. In addition to this, however, given the sensitive history of learning disability policy, it is also easy to see why as an organisation they would not want to be seen to reject these objectives, which were presented through policy as the means by which the lives of people with learning disabilities could be improved.

## **Domestic responsibilities**

The views presented above, about how supported living could act as a transformative force within learning disability support, as I have already stated, clearly echoes national policy. As a supported living property, Sanderstead View, one of my core fieldwork sites, provided me with opportunities to observe what was happening in this type of service. Over the course of the fieldwork, it became clear that a common subject that engaged support workers and the young men living at Sanderstead View was that of domestic responsibilities. Indeed, I learnt that as part of their contract with Singertree Trust the young men, Joey Tammer, Sam Treadwell and Mark Whyatt, were expected to take responsibility for all their household duties, for example cleaning, cooking and doing house food shops. In accordance with this, the staff at Sanderstead View, James Walter, the house manager, and Emily Gillies and David Smith, the two permanent support workers, described how, because this was the young men's home, it was important that they took on these kinds of responsibilities commonly held by other people living in the community.

In chapter five I described how Joey moved into Sanderstead View soon after I started fieldwork, and had arrived there from a residential care home. I also described how the decision for Joey to move into a supported living setting was made by Joey and Singertree Trust because the residential care setting was not appropriate – his freedom was too restricted, and the people he was living with were much older than him. Initially, Joey's support workers at Sanderstead View described how they were pleased with what they saw as Joey's positive attitude towards cleaning and being generally "very active". This contrasted with the other young men, Mark and Sam, who the support workers described as "lazy". However, later in the fieldwork, I observed how the support workers appeared to have developed a different opinion of Joey. For example, one of the permanent support workers, David, commented to him one day:

"You're not cleaning the kitchen, are you ... you're not doing it properly ... you need to keep on top of it ... Joey, there needs to be more of an effort to keep everything hygienic" (field notes, 13<sup>th</sup> November 2014).

On another occasion, after returning to the house from a trip to the Cinema with one of the young men, Sam, we were greeted by a support worker, Doris. Although Doris was not one of the three permanent members of staff based at Sanderstead View, she was well known to Sam and the other young men. Sam and I walked into the kitchen where Doris greeted us and told Sam that she had prepared dinner for him and the other young men. She also said that she had cleaned up, and then asked Sam why he “had left things in such a mess”. Sam seemed to be embarrassed about this, saying that it was not him (field notes, 27<sup>th</sup> August 14).

Elsewhere, staff at Sanderstead View were required to arrange days that house food shopping trips were to take place. As everyone needed to contribute to the running of the house, these trips needed to be on days when all the young men were free to go. Similarly to cleaning responsibilities, the topic of food shopping was regularly discussed between the staff and young men and was viewed by staff as something for which the young men should take responsibility. During one house meeting at which I had been present, the discussion indicated that support workers could experience difficulties in encouraging the young men to agree to accompany them food shopping. Support workers Emily and David told the young men that it was not the role of the support workers to do this job for them. Given this, they were not going to do the food shop without the young men. One support worker, David, said “I don’t think I should have to do that with three of you in the house”. During this conversation, Mark tried several times to speak about other things, such as the code for the cable box, which had been forgotten and so it was not possible to access cable TV channels, and going to play pool, to which Emily then said, “I think the most important thing is shopping”. She followed this with the statement, “we aren’t here to entertain you, we’re here to support you”. David then added the following to Emily’s statement:

“Everyone needs to understand that before the fun stuff can happen, the basic household stuff needs to happen. So, the cleaning, the cooking, the shopping. All that kind of stuff needs to be taken care of before we can take time out and organise the fun stuff for you guys, because like I say, all the stuff we do, all the trips out and you know all

that kind of stuff we do, we take time out of our lives to do that stuff for you guys. So, for that kind of stuff to happen you guys need to take responsibility for the shopping, the cleaning, the cooking.”

During the rest of the meeting, Emily and David continued to ask the young men if they would be able to go shopping together, to which Mark said, “I don’t want to miss my programmes” and Sam said, “I wanted to watch a film” (Sanderstead View house meeting, 13<sup>th</sup> November 2014).

Sarah Hill’s comments in the previous section pointed towards the purpose of supported living as being about enabling access to choice for people with learning disabilities. For the support workers at Sanderstead View, however, it was issues relating to responsibility that often dominated their lived experiences and interactions with the young men they supported. Indeed, as I described in chapter two on p.54, within policy documents responsibility is articulated as a necessary aspect of life that accompanies living in the community and being enabled by social rights (Department of Health, 2009a: p.15, para.16). Certainly, the attempts by support workers at Sanderstead View to encourage the young men to take responsibility for domestic duties such as cooking, cleaning and food shopping could be viewed as reflections of the kind of responsibilities that are mentioned in policy. In this sense, through the support workers’ actions towards the young men, we can see the attempts to mould them into specific types of self-sufficient and responsible citizens.

Conversely, however, the young men at Sanderstead View appeared to take little interest in their domestic duties. They appeared to be happy for these to be completed by staff, for example when Sam had left the kitchen in a mess for Doris to clean. As a result of these conflicts in expectation, I observed how interactions relating to domestic duties often appeared to be a source of tension between the staff and the young men, as the support workers and house manager spent much of their time trying to persuade the young men to take on these responsibilities. Indeed, as I have relayed above, this tension would often result in frustration for the staff, and they would often tell me that they felt the young men were “lazy”.

The use of the term “lazy” can be seen to reflect the support workers’ frustrations with the young men they were supporting. Yet, this frustration can perhaps be empathised with when taken into consideration in the context of policy objectives. Support workers Emily and David understood that their role was to encourage the young men to take responsibility for their everyday lives, which could be viewed as according with the expectation that with freedom comes responsibility. In the context of Sanderstead View, this did mean that the support workers were not there to take on what could be described as caring roles for the young men, but instead to enable them to do these things for themselves. Ultimately, the conflicts that often occurred between the young men and the staff regarding domestic responsibilities did so because the expectations that the young men had of their staff did not accord with the ways that policy was directing the staff to work.

It might be interesting here to think about what these issues relating to domestic responsibilities illustrate about power relations between people with learning disabilities and the people supporting them. It could be suggested that the refusals by the young men to engage in domestic responsibilities could be viewed as an exercise of power of sorts. Although the young men were arguably not experiencing the sense of powerlessness that was invoked by Sarah Hill’s descriptions above of living in the long-stay hospitals, at Sanderstead View they still experienced many restrictions over what they wanted to do. In this sense, perhaps ignoring their domestic responsibilities enabled them with a sense of, albeit small, control over their lives.

### **Personal physical contact**

In other areas of Singertree Trust’s support, the organisational policy instructed support workers to maintain ‘professional relationships’ with the people they were supporting. This organisational policy reflected national policy through the Care Act 2014, which states that as ‘regulated professionals’, individuals working in health and social care are obligated to comply with professional standards set by their regulating body when interacting with the people for whom they provide care and support. This national policy is an attempt to safeguard vulnerable adults

from risk of abuse and exploitation. Here, the concern relates to the difficulty of regulating personal relations in this context, which has consequences for organisational accountability.

Despite Singertree Trust's organisational policy relating to physical contact, throughout my fieldwork I observed many times when people with learning disabilities would attempt to physically engage with the people supporting them. In response to this, Singertree Trust staff generally appeared to be concerned that the people they were supporting would get the wrong idea if they accepted requests for physical contact, such as hugging. This seemed to be about a concern that the people with learning disabilities would mistake the physical contact for confirmation of an intimate, perhaps even romantic, relationship. Indeed, this issue about people with learning disabilities confusing the types of relationships they have with people around them is more widely acknowledged amongst national organisations supporting people with learning disabilities (Owens, 2016). This perhaps also speaks to wider issues of how relationships within state services will always be bounded by the limits of professional relations, and so in this sense, they can never replace those relationships that are formed outside of professional contexts.

During a trip to a local shopping centre, I saw Joey try to take the hand of one of his support workers, but she quickly pulled her hand away from him, without verbally acknowledging what had happened (field notes, 22<sup>nd</sup> January 2015). Elsewhere, during my time with Mark and Joey at their employment training service, Pigtree Farm, I saw how they both, though especially Mark, would regularly attempt to engage in physical contact with their farm support workers, Jane Davies and Samantha Hake. Though I observed that Jane and Samantha would often make attempts to brush off invitations of physical contact or try to distract Mark and Joey with other activities, there were occasions when the support workers responded to these invitations for physical affection. When I asked Jane what she thought was the best response in these situations, she said that, especially with Mark, it was difficult because if you paid him too much attention, he would begin to "play on this". She said it was difficult to achieve a



balance between supporting his needs, whilst not encouraging the “attention seeking behaviour” (field notes, Thursday 16<sup>th</sup> September 2014).

There were also times when people with learning disabilities with whom I was spending time would try to engage me in physical contact. Mark attempted to do this during the house meeting at Sanderstead View which I have discussed above on pp.168-169. Immediately as the meeting began, Mark, who was sitting on the sofa next to me, leant over towards me and put his head on my shoulder. In response to this, support worker David immediately asked him to stop, saying, “not appropriate, mate”. David then appeared to speak to Mark in a soft tone, saying, “I know, it’s just that, I know. Chill. I know you’re feeling nervy and want a bit of reassurance” (field notes, 13<sup>th</sup> November 2014).

On another occasion, when I was with Mark and Joey at Pigtree Farm, we were sitting on a wall waiting for Mark and Joey’s support workers to arrive. Mark again leant over to rest his head on my shoulder. I then asked whether he was “ok”, and put my arm around his shoulder. After a short while, a male support worker from another section of the farm walked past us and explicitly advised me not to let Mark do that, commenting that he would be likely to take it the wrong way. He then told Mark that he knew he shouldn’t be doing it. Mark immediately moved his head away from my shoulder. Later that day, Joey tried to hold my hand, and I found myself replicating the same response as I had witnessed by support workers – I attempted to quickly brush off the request without any verbal acknowledgement.

Arguably, the requests by people with learning disabilities to engage in physical contact could be described as a desire to be cared for. At times, it was apparent that staff overtly rejected invitations to engage in physical contact with people they were supporting. For instance, in the previous section on domestic responsibilities, support worker Emily indicated that she viewed her role as being there to “support” rather than “entertain” the young men. This indicated that she was differentiating between more intimate kinds of support, such as entertaining, with supporting people in instrumental ways, such as with household tasks and food shopping. Indeed, during the house meeting I described above, the support

workers were adamant that their role was to support with instrumental tasks. They went as far to say that the entertaining that they did do for the young men was not part of their support work role, but rather something for which they gave up their own time.

At other times, however, support workers appeared to be conflicted about how to act in these situation, as they would temporarily respond to these calls for care. As I observed with support workers Jane and Samantha at Pigtree Farm, who would sometimes momentarily let the young men hug them, but would quickly break away and attempt to move the situation on. Similarly, during the situation at the Sanderstead View house meeting when Mark leant towards me, I recalled how support worker David had been quite perceptive in interpreting Mark's call for comfort as feelings of nervousness. Though David was aware that physical reassurance was not permitted, he appeared to attempt a verbal approach at providing this to Mark.

Indeed, despite support workers and other staff members appearing to make efforts to maintain professional boundaries with the people they supported, after only a short time in the field, it became evident that, at times, these boundaries were difficult to maintain. In chapter four on p.123, I described how Nigel Sutton, the locality manager, felt that my presence was a good opportunity for the young men at Sanderstead View to do things they could not normally. I also found that, even if support workers felt that it was not their role to provide the kinds of entertaining support that support worker Emily described, they were aware that people were missing out on this. For instance, when I first began my fieldwork, I had conversations with staff at Sanderstead View about what I would be doing on my visits. Here, they expressed a keenness for me to go out with the young men to places like the cinema. They described how, because the young men, especially Sam, had so few hours of funded support, they would often miss out on social activities because their supported time needed to be used for task-based activities, such as domestic responsibilities.

As I have described, not responding to requests for physical contact was in accordance with organisational codes of conduct at Singertree Trust, as well as

government policy. However, it is also an important point to make that support workers' and other staff members' responses to the people they supported could also have been indicative of their need to protect themselves emotionally from the difficulties of their work. The processes of support work are, in many ways, highly demanding in that the people being supported are reliant on others in myriad ways. This then could be seen as resembling the kinds of processes that Isabel Menzies Lyth found in her 1959 study on nursing, which I discussed in chapter two on p.52 (Menzies, 1960).

### **People with learning disabilities getting into trouble**

The conflicting expectations placed upon staff regarding how to respond to the emotional needs of the people they supported was also evident when the people they were supporting were getting into trouble. Getting into trouble was an issue that I observed arose most frequently with two of the young men at Sanderstead View, Joey and Sam. This was most probably because these individuals were allowed to leave their home unaccompanied by support workers.

I have already described how, during Joey's first few weeks of living at Sanderstead View, there initially appeared to be few problems between himself and the staff supporting him. In actively doing his household chores without being asked, he was described by the staff as an independent young man who regularly "did his own thing". However, after a few months of living at Sanderstead View, I observed how relations between Joey and his support staff had become notably strained. Joey had been permitted to spend time away from the house on his own. This permitted freedom, however, had been agreed – through a pre-agreed written document – on the condition that Joey used his mobile phone to report back to staff while he was out. After some months, however, the support workers at Sanderstead View, David and Emily, told me that Joey was returning home after his agreed curfew. They also described how he would often fail to answer his mobile phone when staff tried to get in touch with him. Joey was not successfully adhering to his contractual relationship that had been put together upon his moving into the house.

What was interpreted by support workers as Joey's continual disregard for the terms of his contractual relationship eventually culminated in an incident involving the police. After staying out late one night and drinking, Joey returned home and proceeded to make numerous calls to the emergency services, requesting the fire services. In total, Joey made around 18 calls to the emergency services, which eventually resulted in police involvement. Given that Joey was considered to be an 'adult at risk', Nigel Sutton, the locality manager, was called to the house to act as an 'appropriate adult' to support Joey (Care Act, 2014). However, Joey was not arrested as the police felt uncomfortable taking someone with a learning disability into custody.

A couple of days after this incident had taken place, I visited Sanderstead View. Here, I observed an encounter between Joey and his support worker, David, in which Joey approached David and placed his hand on David's shoulder in what appeared to be a greeting gesture. David responded by moving his arm away, asking Joey why he was smiling and said, "we give you all the freedom in the world". Joey said that he was sorry, but David told him that it was too late as he had used all his chances (field notes, 19<sup>th</sup> March 2015). During my visit that day, David and the other staff at Sanderstead View expressed their frustration that Joey had appeared to be receiving special treatment from the police. They described how, if any of them had done this, they would not have been let off by the police.

I also discussed the incident that occurred with Joey during a formal interview with Nigel, the locality manager who was called to Sanderstead View to act as an 'appropriate adult'. Recalling the incident, Nigel also expressed his frustration, saying that he was dismayed when the police informed him that they were not intending to arrest Joey because he had a learning disability (field notes, 2<sup>nd</sup> April 2015). Elsewhere during this interview, Nigel also referred to another incident involving one of the other young men living at Sanderstead View, Sam. Here, he pointed out that when Sam had recently got caught shoplifting, which was something that had happened before, a similar situation occurred in which the shop did not report Sam to the police. Nigel described how he felt that the shop

staff responded to Sam in this way was because of his learning disability, which he believed was not the appropriate response:

“If you went up to Greggs now and stole you would be arrested. End of. Sam used to go up there and he wasn’t, because he has a learning disability. And, my argument has always been, but we’re not teaching them anything. And, I know that’s a bit of an extreme, but people have to learn about the consequences of their actions and they have to understand.”

Nigel explicitly made the comparison between people without learning disabilities and Sam, a person with learning disabilities. It was Nigel’s view that there should be no difference in the punitive treatment each received, if they were exposed as having committed a crime. He felt that going soft on people with learning disabilities would not help them to learn a sense of responsibility. As I described above, I observed that this view was met by the staff at Sanderstead View. In, for example, David’s reaction to Joey after the incident when Joey had made calls to the emergency services. I also saw that this was a source of much tension and aggravation for staff, in that when laws were broken and no formal charges were made, they found it difficult to accept that the young men were being let off. During the interview with Nigel, I asked him to go further on the issue of responsibility, after which he described how responsibilities:

“are a massive thing ... if you look at something really modern and funky, people would say they’re amazing, if you look at the Reach Standards, there are 11 key standards ... but, there is one missing, and that is that nowhere on those do you say that part of life is having real conversations, and then dealing with the consequences of those real conversations. You can’t say, in the Reach Standards it says everyone will have the same rights and responsibilities as all other citizens, because we’re not saying that. If you truly want that, you have to have really difficult conversations, *i.e.* if you steal you will get arrested. End of. At the moment, that doesn’t really happen.”

The Reach Standards that Nigel referred to above were described in chapter one on p.41. As described here, these standards were created to:

‘ensure that supported living focuses on ensuring each person is able to live the life they choose with the same choices, rights and responsibilities as other citizens’ (Paradigm UK, 2017).

As Nigel stated, these standards indicate the need to ensure that people with learning disabilities have the same rights and responsibilities as other citizens. In this sense, there is an acknowledgement that freedom of choice must be balanced with personal and social responsibility. Clearly though, it was Nigel’s belief that Joey and Sam at Sanderstead View were not fulfilling these conditions.

Nigel described to me that he felt these problems were occurring because there was a deep misunderstanding of the foundations of the Mental Capacity Act, in terms of how to determine capacity of a person with learning disabilities. He felt this misunderstanding existed within the local authority, as well as amongst families and the general public. It was Nigel’s opinion that bad choices that people with learning disabilities made were all too quickly interpreted as that person not having capacity. To illustrate his point, Nigel used the incident of Joey making the numerous calls to the emergency services, saying that Joey was aware that what he had done was wrong, but “it doesn’t mean because he’s ignored it that he doesn’t have capacity. That’s where I think we’re getting in a real muddle with stuff”.

The problem this caused, Nigel stated, was that people with learning disabilities were neither being taught about acting responsibly nor about the consequences of their actions. I then asked Nigel whether he thought Joey had fully understood the consequences of his actions that night when he made multiple phone calls to the emergency services. Nigel said:

“Possibly what he doesn’t understand is why he gets in trouble ... maybe he thinks that’s what the emergency services do, if you call

them they come out and say hello. He thinks there's an unlimited number of fire engines."

I then asked Nigel whether that was evidence of Joey not understanding the consequences of what he had done. Nigel replied:

"There's a lot of work to be done around consequences. That's why he should have been arrested because that's the consequence. Nothing has happened, he wasn't arrested. You or me would have been. That should have been a consequence and it wasn't."

I then asked Nigel some further questions about Joey's level of understanding, this time in relation to the other issue of him not adhering to his curfew times. Nigel responded:

"Again, that's the same thing. You're accepting and assuming someone has capacity, and then your duty of care is we need to try and keep someone safe as well. In my opinion, and in his mum's opinion, and in the local authority's opinion, and in his social worker's opinion, it's not safe, it's not good for Joey to be just wandering the streets at 11 [p.m.] ... so we have boundaries and agreements. Not to curb his freedom, cos he's free not to come home. What we're saying is, if you want to live at Sanderstead View, we have a duty to try and keep you safe. Also, you have two other people you share with so you can't be rocking up at one in the morning and waking people up, that's a breach of your tenancy. People shouldn't think that we're reckless with capacity, it doesn't mean that you can do whatever you want...that's all we're saying, there are consequences to your actions" (interview, Nigel Sutton, 2<sup>nd</sup> April 2015).

As I have described, because they were given certain freedoms to leave their home unaccompanied, I observed that the issue of social responsibility was a particularly salient one for Sam and Joey at Sanderstead View. These examples I have provided where the two young men were getting into trouble are revealing

of the complexities involved in determining whether they were able to fully grasp the consequences of what they had done. As I described in chapter one on p.42, under the Mental Capacity Act, capacity to make decisions must be determined on a case by case basis, or in other words, relating to a decision in a specific matter (Mental Capacity Act, 2005). However, determining this heavily relies on drawing verbal responses from the person themselves. At times, I observed that people with learning disabilities appeared to respond to staff members in ways they anticipated what the staff members wanted and/or expected to hear. For instance, Sam and Joey may have verbally acknowledged their mistakes, yet determining the full extent of their understanding was perhaps more complex. Given the nature of these dynamics, capacity could be, and has been by others, interpreted as highly relational rather than individual (Kittay, 2011). Indeed, further still, this also indicated the susceptibility of the young men to alter in accordance with others around them. This apparent fragility of their sense of selves surely meant that determining the extent of their understanding using capacity assessments, which are premised on the notion of capacity to make decisions from a rational and independent viewpoint, may have been distortive.

As such, if Sam and Joey did not fully understand the consequences of their actions, should they have been punished in the way that Nigel and the staff at Sanderstead View were calling for? Perhaps this is suggestive of the need for boundaries in this context to be negotiable. Yet, when thinking more broadly about determining capacity of people with learning disabilities, this issue is a highly complex one to make generalisations about, given that each individual experiences their disability in highly heterogeneous ways.

### **Policy expectations of responsibility versus the reality of lived experiences**

The complex issue of responsibility in the lives of the people with learning disabilities who were being supported by Singertree Trust emerged as a common thread throughout my fieldwork. During the time I spent with Joey, I observed how, at times he was capable. I have described how, at Pigtree Farm, he worked hard and actively sought out jobs to do. He also appeared to independently decide to engage in employment opportunities. For example, after moving into



Sanderstead View, he found some volunteering work at a nearby charity shop. Moreover, each year he volunteered at a local hot air balloon festival, which he did so out of a love of hot air balloons.

Yet, although Joey could appear as highly capable and independent, he could also seem to be vulnerable and unsure as to what to do. The first day I met him he told me that when he had been travelling on a bus the previous day his wallet had been stolen (field notes, 9<sup>th</sup> September 2014). Upon first hearing this story, I assumed that this was a one-off incident of bad luck, especially given that the staff at Singertree Trust had agreed that Joey could leave his home alone. However, as I spent more time with Joey, I began to sense that the incident with the wallet was not an isolated one. During my time spent with Joey, I also observed that he may have experienced difficulties in telling the time on clock faces. Furthermore, on several occasions he told me that his mobile phone wasn't working, usually because there was no credit on it. On one occasion, however, he told me he had dropped it down the toilet and wasn't sure how to make it work again (field notes, 9<sup>th</sup> September 2014).

Whilst on my final day of fieldwork spent with Joey, he told me that he had been sexually assaulted in a pub the previous evening. Joey told me that he had already reported this to his key worker. In addition to this, another support worker had been present when Joey had relayed this information to me, and so I decided not to discuss this issue with anyone else. I was also aware, from overhearing discussions amongst staff earlier in the day, that they were aware of what Joey had reported to them.

Given these incidents, there were times when I considered that his support workers were treating Joey unfairly, and not recognising his vulnerability. For instance, I was concerned that the difficulty he experienced in telling the time and in understanding how to work his mobile phone could possibly have contributed to his inability to adhere to the curfew rules set by the staff at his house. Saying this, however, determining what was actually going on with Joey and his support workers was complex. Despite my sense that Joey's inability to comply with the conditions of his curfew may have been, in part, because of his lack of ability to

tell the time or work his phone, there were other aspects to consider. I have already described the difficulties in deciphering whether the young men, Sam and Joey, fully understood the consequences of their actions when confronted about them. In similar ways, through the course of the fieldwork I became aware that some of the people with learning disabilities I spent time with appeared to try to elicit caring or sympathetic responses from support workers by presenting themselves as vulnerable or in need of protection. Indeed, I also felt that some people would tell me things in the knowledge that this would bring about a sympathetic or concerning reaction. After some time, I began to sense that this may have, in part at least, explained support workers' lack of action or concern relating to these behaviours. For instance, Joey claiming confusion about his curfew times or that he had been abused in a pub could have been viewed by support workers as part of a performance by him to avoid abiding by the rules and/or to get attention.

Given that the support workers at Sanderstead View may have regularly experienced this kind of behaviour from Joey, as well as perhaps from the other people they supported, it would be understandable as to why they often appeared to be unaffected or unconcerned about these kinds of claims. Despite this, however, that Joey, and possibly others, acted in these ways could be evidence of the lengths they would go to in order to try to influence the way staff members were relating to them. In this sense, this behaviour may have been indicative of deep-rooted issues underlying the social relations between people with learning disabilities and the people supporting them, in terms of how relations between the two groups were being distorted by the unattainable expectations that were being forced upon each one.

The complexities of enabling people with learning disabilities to take responsibility for their actions was also discussed during the formal interview with Sarah Hill, the operations manager at Singertree Trust. Here, Sarah told me about a woman with a learning disability who was receiving support from Singertree Trust. Sarah described how the woman was vulnerable, yet this vulnerability did not seem to be recognised by social services because the woman was considered to have capacity:

“We had somebody who was really at risk. Really at risk, this lady. She was a lovely lady, but she would go off base-line and she was at risk to herself. She would go down town, she would wear the most skimpiest clothes that you could imagine. She’s a lady in her 50s, erm, she would sell herself. She would get in with the wrong crowd, she would erm take drugs, everything. We needed more support for that lady, we were asking for more support, she needed more support, and all we got told is, ‘she’s got capacity’.”

Sarah then went on to describe the disastrous events that unfolded, which she directly associated with the lack of support that the woman had been provided:

“And she would turn up at the social services office, and her lead social worker and say, ‘I’m not going back to’ where she used to live. ‘I want my own flat, I’m going to make myself homeless’ [to which the social workers would say] ‘that’s your choice because you’ve got capacity, if you want to do that, we won’t support you’. We were really concerned about her safety, and she was vulnerable, everything and we thought that people could take real advantage of her. It got to crisis where she was detained under the Mental Health Act and then put into Winterbourne View. She should never have gone into that service.”

Following this, I asked Sarah what the solution was here. Was it acceptable to curb the freedoms of people with learning disabilities to ensure that they were being kept safe? She replied:

“With people with a learning disability it’s really difficult to deem whether they’ve got capacity or not. There’s a really fine line. I haven’t got a learning disability, but if I chose to stay out until 6 o’clock in the morning drinking, and I chose to start phoning up the police, ambulance and start messing with bogus phone calls and everything else, I would be charged, wouldn’t I? I would be arrested and I would be charged. If I had a learning disability and I’d been deemed that I’ve got capacity and I did exactly the same, the police wouldn’t charge me.

So, you can't in one breath say that someone has got capacity and then not treat them the same as me. If they've got capacity, you have to treat them in the same way that you treat everybody else. But, with learning disability, I think that people always forget this. They may have a certain amount of capacity, but you have to remember that that person's got a learning disability. There's some part of their brain that is damaged, it's not working correctly, and it's different parts for different people ... so have they really got full capacity? If they had full capacity, they wouldn't be classed as having a learning disability, would they?"

From her remarks, I sensed that Sarah was referring to the incident I have described above when Joey had made the numerous calls to the emergency services. I ventured to ask her about this and what she thought should have happened with Joey, to which she said:

"Arrest him. They are saying he's got capacity and he knows what he's doing ... so, if he hasn't got capacity and he doesn't understand what he's doing, take his phone off him, don't give him any access so that he can actually do that. Don't let him go out, because there is a risk. But, oh no, he's got capacity so he can do that. You can't have it both ways."

Here, Sarah was echoing Nigel's views above about arresting people with learning disabilities if they commit crimes. However, unlike Nigel, she was not making this statement because she believed that people with learning disabilities should face punitive punishment, which would enable them to learn the consequences of their actions. Instead, Sarah highlighted what she saw as an ill-conceived legal view of capacity in respect to the lives of people with learning disabilities. Indeed, Sarah agreed with Nigel that it is a contradiction if someone is considered to have capacity but are not then made to face the consequences of their actions. However, she also pointed out that consideration should have been given to whether he was able to take on the responsibilities that came with ownership of a mobile phone. Sarah's argument was clear when she pointed out

the inescapable reality that people's learning disability will always inhibit their ability to make rational judgements, "They may have a certain amount of capacity ... [but] If they had full capacity, they wouldn't be classed as having a learning disability, would they?" (interview, Sarah Hill, 20<sup>th</sup> March 2015).

In response to the illegal and/or risky behaviour of people with learning disabilities, I have described that Nigel advocated for a learn-by-doing approach. In this case, learning through facing the consequences of one's actions. Importantly, however, this stance relies on the ability of people with learning disabilities to be able to understand and learn from their mistakes, which Nigel believed was possible. Indeed, it was his view that damage was being done by not showing people that they were required to face the consequences of their actions, as this meant that they were not learning valuable life lessons. This is not to say, however, that Nigel was dismissing the difficulty of attempting to balance giving people freedom with protecting people from harm. Indeed, elsewhere in the interview, Nigel referred to the organisational strategy at Singertree Trust, which as I described at the beginning of this chapter, was actively moving towards service provision that promoted people's independence and community inclusion. Here, Nigel acknowledged the complexity of and risks around giving people with learning disabilities freedom, which he felt was not acknowledged by members of the organisation who worked away from front-line support:

"That's what the Trust are trying to do with all their new branding, this freedom stuff, that's what it's all about. All of that stuff is good, but all of those people doing the branding, I think they need to sit in on some of these big strategy meetings that you get pulled in on, because it's easy on a piece of paper, saying yeah yeah it's great, we're gonna let people have freedom. That's fine, but come and find out what it's really like, when you really give people freedom and it goes wrong."

Despite acknowledging the complexity and possible risks involved, Nigel remained resolute that it was crucial to move away from erring on the side of risk avoidance, because being able to decide for yourself is "a fundamental human

right” that should not be denied to any person (interview, Nigel Sutton, 2<sup>nd</sup> April 2015).

On the other side of the coin, Sarah’s stance could be erring on the side of risk avoidance in that she was calling for people to be prevented from engaging in certain behaviours before they took place. Her argument was based on the grounds that it is unavoidable that people’s material condition will impair their ability to process information to the same complexity as people without this condition. Clearly Nigel’s stance was correct, that people with learning disabilities, such as Joey, could not be given the best of both worlds; he could not have freedom to do as he wished without facing the consequences of his actions. However, what must be questioned is the extent to which, even with education and support, whether as a young man with learning disabilities, Joey would be able to understand the consequences of his actions in the same ways as is expected of people without this condition. It is crucial to repeat the point here that has been made elsewhere in this chapter and thesis, that making definitive decisions and generalisations about the lives of people with learning disabilities can be both misleading and unhelpful. However, the general point needs to be made that just because people may be aware of the choices that they want to make does not necessarily mean that they are able to fully take on the kinds of obligations and responsibilities that accompany these choices. Surely, to ignore this fundamental aspect of the material existence of people with learning disabilities is to lumber another form of disservice upon them: unrealistic expectations.

### **Chapter conclusion**

In this chapter, I have explored how support workers and other staff experienced policy objectives within the context of everyday support, and how this influenced the ways they related to the people they supported. The two approaches presented by Nigel and Sarah above broadly sum up the complexities of trying to achieve a balance between supporting people with learning disabilities to live with the different identities that have been constructed for them through policy – of the

different kinds of freedoms they should be enabled with, as well as the need to protect them from harm.

The ethnographic findings presented here in chapter six, as well as in chapter five, show how the expectations that policy objectives placed on support workers and other staff, in terms of how to relate to the people they were supporting, could be both unrealistic and unresponsive to people's needs. These expectations often appeared as being beyond what was attainable for people with learning disabilities. Moreover, they did not appear to accord with the expectations that people with learning disabilities themselves had of how to be supported, as they tended to seek informal and emotional support. In this sense, perhaps what people with learning disabilities required was a form of bounded liberty that depended on negotiations with others. Granted, these boundaries might be more narrowly defined for people with learning disabilities than for those without this condition. However, all experiences of liberty exist on a spectrum, with different people being afforded greater or lesser amounts according to their circumstances. I argue that the conflicting expectations between support workers and people with learning disabilities were damaging for their relationships. Ultimately, this had a negative impact on the ability of support workers and other staff to provide good care to people with learning disabilities. In the following discussion and conclusion chapters, I will explore these interpretations in greater detail.

## Chapter seven

### Discussion

#### Introduction

In this chapter, I begin by providing a summary of the thesis so far. From here, I draw together and develop further the themes that emerged across the previous empirical chapters five and six. These chapters presented the ethnographic findings which showed how people with learning disabilities, support workers and other staff experienced policy objectives in the everyday context of social care support. The findings indicate that, rather than working as an emancipatory force in people's lives, when played out in everyday practice, the aspirations of policy objectives were not always compatible with the lived experiences of people with learning disabilities and the people supporting them. Here, I will explore this in greater detail through the overarching themes of the performative effect of policy expectations; the unavoidable reality of exclusion; emotional labour; and the flaws of liberal and social democratic politics for people with learning disabilities. I will end this chapter with a discussion of the implications these findings have for policy and practice.

*'There are indeed many precautions to imprison a man in what he is, as if we lived in a perpetual fear that he might escape from it, that he might break away and suddenly elude his condition' (Sartre, Being and Nothingness, 1956: p.122).*

#### **A summing up of the thesis so far: a challenge to the rhetoric of policy**

As was presented in chapters one and two, this research is set against a backdrop of government policy that aims to enable people with learning disabilities with particular kinds of independence and community inclusion. Chapters one and two showed how, in aiming to achieve this, policies have



sought to construct people with learning disabilities through various identities, including citizen, consumer, employer, employee and friend. These identities also sit alongside constructions of people with learning disabilities as vulnerable adults, in need of protection. All are underpinned by differing, and often conflicting, social, political and economic philosophies which articulate changing perceptions towards state-citizen relations.

From the beginning of the 20<sup>th</sup> century, protecting people with learning disabilities from risks posed either by others or themselves had remained a central tenet of policy in this area. Yet, from the mid part of that century, policy then began to alter in accordance with wider societal views pertaining to the belief that all people, irrespective of their disabilities, were equally entitled to rights and freedoms afforded to non-disabled citizens. These changing societal views were reflected through transformations in models of care, from large-scale institutional settings into community-based living. This change was viewed as enabling people with citizenship rights and inclusion into community life.

From the 1970s, the New Right introduced the idea that it is the market, rather than the state, that enables individuals to flourish. With this, parts of social care were reorganised, and there was a move away from nationalised provision and towards state-regulated but independently-run service delivery. Then, the vision of the Third Way aimed to reconcile the need for both social policy with the growth that capitalism ensures. The implications of this for contemporary learning disability support is that today there is a complicated mix of state, private and third sector organisations providing support to meet people's needs. Entwined within this mix is also the assortment of social, political and economically driven policies which have attempted to provide solutions for how people might best be provided the support they need to live fulfilling lives.

Through ethnography, I explored how the various constructed identities of people with learning disabilities were experienced in everyday practice. As well as often being incompatible with each other, the ethnographic findings presented in chapters five and six indicate that these various identities and the aspirations attached to them – achieving independence, paid employment and having

relationships outside of services – often failed to recognise the material impact people’s cognitive impairments had on their lived experiences and relationships with others. Furthermore, rather than viewing their support staff as vehicles through which these identities could be realised, people with learning disabilities often sought more informal and emotionally-driven connections from the people supporting them.

Yet, the focus within policy that these identities and aspirations should be considered as aspects of a ‘normal’ life was such that, in the context of daily practice, the emotional needs of people with learning disabilities could get ignored. Instead, support staff, and at times people with learning disabilities, were compelled to partake in a performance through which there were attempts to enact policy aspirations. This performance served to maintain the perception that empowering people with various kinds of autonomy and a life in the community could be achieved, when in fact, these imperatives were often shown to be incompatible with what was possible for people with learning disabilities. In the context of everyday practice, I found that tensions arose from these incompatibilities which could result in confusion and frustration for both people with learning disabilities and their support staff. Despite the goodwill driving policy aspirations, there is evidence here to suggest that if they are not achievable they could be thwarting people’s ability to reach their full potential, in whatever mode or capacity that may be.

### **The relationship between policy and practice revisited**

In taking an ethnographic approach to this research, I have fundamentally been concerned with how care and support are understood and enacted between people in the micro-contexts of their daily lives. On a broader level, however, these context-specific dynamics are relationally entwined with the wider structural influence of policy, which as I have described, has constructed a range of identities for people with learning disabilities. Importantly, the relationship between policy and practice is not straightforward in that policy is not played out in everyday practice as it is written (Lipsky, 1980). Certainly, the findings from this study corroborate this argument, as policy goals of achieving independence

and community inclusion for people with learning disabilities were often not played out in the ways described through policy documents.

In his work, *Street-Level Bureaucracy: Dilemmas of the Individual in Public Service* (1980), Michael Lipsky challenged the perception that policy objectives are straightforwardly translated into everyday service settings in a top-down way. He popularised the term, 'street-level bureaucrats' to describe the government employees who physically implement abstract policy ideas. Here, suggesting that, despite their typically being in low-paid and low-status roles, because of the freedom and discretion they can exercise when interacting with people in receipt of policy objectives, 'policy implementation in the end comes down to the people who actually implement it' (Lipsky, 1980: p.8). From this perspective, street-level bureaucrats play a significant role in determining the nature of relations between the state and its citizens, 'in short, they hold the keys to a dimension of citizenship' (p.4).

In relation to my own research, these ideas about how policy is interpreted in everyday practice could be seen to emphasise the importance of understanding situated experiences. However, this should not just be about understanding the ways that support staff interpreted policy on the ground, but also how it was interpreted through their interactions with the people with learning disabilities that they were supporting. Indeed, thinking about people's experiences of policy objectives in this way may also go some way to explaining how the abstract ideas of empowerment which are presented through policy appeared to fail to incorporate the relational elements between people with learning disabilities and their support staff. I argue here that policy objectives tended to remain unattainable because they fail to acknowledge, in a coherent way, how people's impairments impacted their ability to both empower themselves and become empowered.

### **The performative effect of policy expectations**

The ways that policy is presented above, in terms of not being enacted in the ways it is written, provides a helpful way to situate the findings presented in this

thesis. I have described how, through government policy support workers and other staff were being directed to relate to the people they supported in ways that would promote and encourage their independence and inclusion in society. In attempting to achieve this, various identities of people with learning disabilities were constructed through policy, the view being that these identities would enable people with learning disabilities to live fulfilling and meaningful lives. However, the ethnographic findings indicate that people with learning disabilities were often unable to live up to the expectations associated with these identities.

Above, I also mentioned that, for the aspirations of policy objectives to be seen to be taking place, people were compelled to engage in a performance. Across chapters five and six, this performance can be seen to be enacted through specific aspects of people's lives, such as care plans, community participation and college courses, as well as more general aspects, such as through a sense of social responsibility. I showed how people with learning disabilities tended not to be able to realise aspirations promoted through policy, independently at least. This resulted in tensions arising in everyday practice between what was expected to take place and what actually took place. Despite these aspirations of independence and inclusion not being possible, their pervasiveness within policy created a climate in which both provider organisations and support workers felt pressure to be seen to deliver independence and inclusion for the people they supported. Consequently, the disparity between policy and people's lived experiences were often masked by performances in which policy aspirations were seen to be enacted.

The ways in which disparities between policy aspirations and people's lived experiences create tensions in everyday life is well elucidated in a study by Alison Pilnick, Jennifer Clegg, Elizabeth Murphy and Katheryn Almack (2011), which looked at the processes involved in transitioning from children to adult learning disability services. Through conversation analysis of in-depth discussions, in which transitions support was being discussed with young people and their parents, Pilnick, Clegg, Murphy & Almack showed how the focus in policy on the self-determination of people with learning disabilities often clashed with the needs and choices of parents. Parents of individuals with learning disabilities are often

required to continue taking on significant responsibility for their son/daughter well into adulthood. As such, focusing solely on the choices of the person with learning disabilities meant that the freedom of the parent(s) was being jeopardised. This indicates the flawed logic in defining freedom in such individualistic terms for people whose condition means they are, to varying extents, reliant on others to enable this freedom.

Another way this performance was particularly starkly indicated was through employment. For instance, the transformations that were taking place within the service at Bristlehedge were indicative of the perceived need to move away from traditional day centres that were viewed as encouraging segregation and towards gearing people for employment, which was seen as enabling them with opportunities for independence and inclusion. This was evident in the attempt by the locality manager, Hannah Stokes, to formally legitimise the NHS medical box packing work that people were doing at Bristlehedge by working to comply with employment law. Yet, to sustain the levels of productivity required for the NHS to justify paying the National Minimum Wage (NMW), much of the workload was passed on to the support worker, Frank. Ultimately, however, this was not sustainable in the long term, and paradoxically, the push to elevate the economic employment status of people with learning disabilities served to jeopardise the work that they had been doing on a voluntary basis. Work, as Frank described, they would have been happy to continue to do for free. However, as was pointed out when Frank was keen to distinguish the NHS box packing work from slave labour, the issue of people with learning disabilities working for free for professional companies was clearly a contentious one with legal implications.

These kinds of contentions surrounding employment for people with learning disabilities was illustrated in October 2015, when a news story broke about comments made by the then Welfare Reform minister, Lord David Freud, during a fringe meeting of the Conservative party conference. The minister was asked by a Conservative councillor:

“The other area I’m really concerned about is obviously the disabled.  
I have a number of mentally damaged individuals, who to be quite

frank aren't worth the minimum wage, but want to work. And we have been trying to support them in work, but you can't find people who are willing to pay the minimum wage. We had a young man who was keen to do gardening; now the only way we managed to get him to work was actually setting up a company for him, because as a director in a company we didn't have to pay the minimum wage, we could actually give him the earnings from that. But trying to maintain his support and allow him to work, which he wanted to do, so to stay with benefits, and stay with some way of managing to continue on in that way. And I think yes, those are marginal areas but they are critical of actually keeping people who want to work supported in that process. And it's how do you deal with those sort of cases?"

Responding to this, Lord Freud said:

"Now, there is a small ... there is a group, and I know exactly who you mean, where actually, as you say they're not worth the full wage and actually I'm going to go and think about that particular issue, whether there is something we can do nationally, and without distorting the whole thing, which actually if someone wants to work for £2 an hour, and it's working can we actually..." (Watt & Wintour, 2014a).

The reaction to these comments was severe. During prime minister's questions on the 15<sup>th</sup> October of that year, the then leader of the opposition, Ed Miliband questioned whether this was the view of government, to which the then prime minister, David Cameron stated, "Those are not the views of the government, they are not the views of anyone in the government. The minimum wage is paid to everybody, disabled people included." (Watt & Wintour, 2014a).

So politically contentious is this area that, following this challenge from Ed Miliband, within 90 minutes of the prime minister's order, Lord Freud had issued the following statement:

“I would like to offer a full and unreserved apology. I was foolish to accept the premise of the question. To be clear, all disabled people should be paid at least the minimum wage, without exception, and I accept it is offensive to suggest anything else” (Watt & Wintour, 2014b).

Lord Freud’s comments were widely criticised by politicians across the political spectrum as being highly inappropriate. Elsewhere, several disability charities, including the learning disability charity, Mencap, also expressed their disapproval of his response to the Conservative councillor’s questions about how disabled people might be supported into work. At the time of this scandal, the then deputy prime minister, Nick Clegg, appeared to speak to the nub of the contention that had erupted following Lord Freud’s comments. He pointed out that in using the word “worth”, Lord Freud had appeared to connect people’s economic value with their “individual value” (Wintour, 2014). In an article responding to the assertion that Lord Freud was connecting the human worth of people with disabilities with their economic worth, Ryan Bourne, of the Institute of Economic Affairs, acknowledges that Lord Freud’s wording was ‘clumsy’, but goes on to argue that:

‘A severely disabled person who finds it difficult doing a particular job can be objectively as valuable as anybody else. But it does not follow that they will receive the same amount in material reward from an employer for their work. The employer is compensating them for their time and effort and rewarding them for what they produce – this is totally distinct from our worth as human beings’ (Bourne, 2014).

Here, Bourne points out how worth as a concept cannot be prescribed in a uniform way to all contexts. In this way, there are different types of worth. A person’s human worth is not altered by their having a disability. However, this may have a material impact on their economic worth to their employer. Nearly two years after Lord Freud’s comments, these arguments continued. In an article in the Spectator in March 2017, this issue was raised again by Rosa Monckton, a campaigner for young adults with learning disabilities and a mother of a young woman with Down’s syndrome. However, rather than take the side of those who

had been critical of Lord Freud, in her discussion on the difficulties of supporting people with learning disabilities into employment, Monckton accuses policy makers of living in 'an abstract world, driven by the idea of 'ending inequality' without looking at the real lives of the people involved' (Monckton, 2017). In Monckton's view, laws governing the National Minimum Wage are obstructing people with learning disabilities from being able to work. Writing in March 2017, she described how the increase in the National Minimum Wage from 1<sup>st</sup> April 2017 would be detrimental for people with learning disabilities in gaining work for the simple reason that employers are less likely to employ people with learning disabilities at these rates because this would increase their chances of working at a loss. The result will be, Monckton argues, that employers will end up taking on fewer people with learning disabilities so that they do not incur financial losses.

The above extracts indicate the ways that this argument had, in some ways, become embroiled in a bitter right versus left debate, mostly about the economic legitimacy of the National Minimum Wage. Unfortunately, this has served to distort much of what this debate should have been about, which, as Monckton points out, was 'the real lives of the people involved' (Monckton, 2017). However, the fact that this debate was taken over by political arguments relating to the legitimacy of the National Minimum Wage, and that it ignited sensitivities about human and economic worth, indicates something important about how people with learning disabilities are constructed through policy, as well as laws and regulations.

Current arguments relating to the minimum wage involve the issue of whether unskilled workers are made worse off by employment laws that employers are required to follow. This is indeed a complex economic area, and one in which there are arguments for and against. However, I think that the traditional arguments used to explore the legitimacy of the National Minimum Wage do not stand up when we are thinking about people with learning disabilities. This is because, for the most part, the issue of work for people with learning disabilities tends not to be about the need to earn money to live or to improve their economic status. Rather, work is about the need to bring fulfilment and meaning to their lives in different ways. Certainly, in an ideal world people with learning disabilities



would engage in work to improve their economic capital, which would provide them with opportunity to increase their social capital. However, just because laws are altered to require employers to pay the minimum wage to people with learning disabilities does not mean that the material problems they experience because of their disabilities would cease and they would become fully included and equal members of their communities. To pretend that this is the case is to ignore the needs of people with learning disabilities and to thwart the chances that they do have to seek fulfilment in voluntary or other kinds of work.

In this same vein, making the assertion that not paying people with learning disabilities the National Minimum Wage is an insult to their human worth is, as Rosa Monckton explains, to 'obsess on the 'human right' of disabled adults' (Monckton, 2017). Indeed, as Monckton goes on to say, positioning disabled people's human rights as paramount can actually serve to disadvantage them further, because this makes the issue about money, and 'in practice, money isn't the real point' (2017). Instead, as Monckton points out, as day centres and other services are closing, the opportunities for people with learning disabilities to engage in social life are lessening. This will only be compounded if laws relating to the National Minimum Wage are not changed. The likelihood is that people with learning disabilities will have access to far less than before.

Granted, providing support and/or voluntary pursuits within social enterprises and/or third sector arrangements does have drawbacks in that there is a danger that people can remain dependent on professional support on the outskirts of communities. However, to refuse people these opportunities on the grounds of abstracted principles that do not accord with their real lives is perhaps to do more of a disservice to these individuals. In returning to the ethnographic findings from this thesis, from a policy perspective the service at Bristlehedge could be described as old fashioned, institutionalised and limiting to people's freedom. Indeed, I did observe that the work of packing medical boxes for the NHS was not appropriate for some of the people, particularly the younger woman at this service. Elsewhere, however, amongst the older individuals this work did seem to be appealing. Furthermore, their attachment to their support worker Frank, enabled them to feel secure whilst they engaged in work in ways they found

fulfilling. Similarly, the work for people with learning disabilities that Steve Connors at Station Park Café was managing could be viewed on these terms. Although this work was voluntary and took place within a protected setting of a church café, the approach Steve took in using work to recognise the contribution rather than the outcome enabled people with varied levels of disability to become engaged and feel valued parts of a whole.

Arguably, there are downsides to supporting people within service-style arrangements. Indeed, in chapter four I tried to convey the sense that people with learning disabilities were, in many ways, living separately from many other groups in the community. However, rather than attempt to fit people with learning disabilities into theoretically abstracted definitions of fulfilment, it may be more fruitful to be realistic about what is achievable for them, and be led by what they themselves find fulfilling. If not, surely we are in danger of providing support that does not meet people's needs, which is a potentially damaging way to relate to disability.

Ultimately, this is about recognising the inescapable reality that people with learning disabilities differ cognitively from people who do not have learning disabilities, and this material difference impacts on their ability to engage with the world around them. To varying levels and in differing ways, people with learning disabilities will experience difficulties in assuming the kinds of rights and responsibilities that have come to define what it means to live a good life, such as paid employment. Perhaps then it is time to think seriously about valuing the types of sheltered pursuits that are possible for people to achieve.

### **The unavoidable reality of exclusion**

It is important to point out that, in addition to the problems relating to the idea that people with learning disabilities can be successfully included in community life, the idea that community life exists in a uniformly describable way is also problematic and requires discussion. In chapter two on p.53, I touched on this when I discussed how some scholars have explored the ways that notions of 'the community' have been expressed in policy as a utopian 'land of milk and honey'

in that access to community life necessarily results in inclusion. As Burton and Kagan describe, *Valuing People* presents community life in terms in which people make:

‘choices about activities in pleasant neighbourhoods, with plentiful community resources. They are supported in this by their own staff, which they employ and who work to their specification. They are likely to be in work, and to have friendships and relationships, mostly with nondisabled people. Somewhere in all this there is the notion of independence’ (Burton & Kagan, 2006: p.305).

Indeed, this uniform notion of community life was echoed in chapter five on pp.136-138, in the comments by Singertree Trust’s CEO, who described how people with learning disabilities need to be able to experience life “just as you or I would understand it” (A Lonely Society, 2016). The idea that community life can be uniformly defined and that people with learning disabilities can be meaningfully fulfilled by moving into this mainstream area is to oversimplify people’s experiences in society. These aspirations are misleading as they give the impression that there are clear-cut inside/outside boundaries between exclusion and mainstream life. Yet, even for people who live without disabilities, the boundaries between exclusion and community remain opaque, as in differing ways and to differing extents people and groups can experience both exclusion and inclusion. In this sense, as opposed to being clearly defined, these experiences could be seen to exist on a continuum.

It is also necessary to point out here that exclusion can be experienced in both constructed and objective ways. For some people and groups, the exclusion they experience relates to discriminatory and prejudicial views that are generated from ill-informed biases, for instance, racist or sexist views. For others, however, the exclusion they experience is because of objective factors, such as physical or intellectual disability. It may also be worth returning here to the work of Robert Edgerton (1967) and Erving Goffman (1963), who I discussed in chapter two on pp.64-66. In exploring the experiences of men and women with learning disabilities after they had left an institution, Edgerton found that they appeared to

be unable to 'shake' off their disability, and that it continued to linger with them. These difficulties of fitting in that Edgerton showed people experienced in community life could be read as a failing on the part of society to alter their stigmatising views of disabled people. However, it could also be argued that it remains objectively more difficult for people who have marked differences to assimilate themselves into social settings where others' differences are less marked. Indeed, Goffman's notion of 'passing' similarly illustrates the desire of people with stigmas to hide what makes them different in order that they can attempt to fit into social life and be considered as 'normal'.

As I also discussed in chapter one from p.30, and in chapter two on p.57, the popular social model of disability theory contends that the exclusion disabled people experience is constructed through institutions and social relations, for example inaccessible workplaces and transport systems, as well as stigmatising views about people who are different from the 'norm'. From this perspective, the exclusions people experience can be dissolved by removing those existing physical and social barriers. However, I also pointed out in chapter two that altering the physical structures of environments is a different process to altering the impaired effects of disability. Further still, I argue that, in the context of people with learning disabilities, their objective intellectual impairments tend to place them towards the far end of the continuum, meaning that it tends to be more difficult still to alter their environments and the people around them in ways that reduce their experiences of exclusion. This is indicative of the reality that the objective nature of some deficits is such that they cannot be defined solely in terms of social constructions. There are material aspects of learning disability that objectively limit people's ability to interact with their world, and which cannot be altered irrespective of perception. In recognising this, the scholar Carol Thomas coined the term 'impaired effects' to interweave the social and material ways that people's impairments can shape their lived experience of the world (Thomas, 1999).

Through my ethnographic fieldwork, I did indeed observe the ways that people experienced exclusion through a complex interplay between how they were socially and materially impaired. For many people their ability to engage with their

communities was limited by the fact that they experienced social anxieties in large and busy crowds. It is difficult to determine the causes of people's anxieties – whether they were because of cognitive and executive functioning, or whether they were caused by social isolation and a lack of familiarity with public life. However, irrespective of the cause, support workers and other staff would have to consider this when leaving the house with people, and trips out would usually be organised when it was anticipated that public places, such as shopping centres, cinemas and bowling alleys, would be quiet. Across chapter five, I described how I accompanied some people with learning disabilities bowling. Indeed, bowling was an activity partaken of by many people I spent time with, and one that they appeared to enjoy. Based on my experience, people would usually go bowling during the daytime on weekdays. One reason for this was probably because it was most practical for support workers to accompany people during their daytime shifts. In addition, however, support workers, as well as some people with learning disabilities, told me that if they went at busy times people with learning disabilities would tend to become agitated, upset and frightened by the large crowds and noises.

The fact that people with learning disabilities tended to spend time in public places at times when other members of the public were not present speaks further to the problematics of engaging people with learning disabilities in their communities. Further still, the way that these aspirations were impacting organisational policy at Singertree Trust indicated how such aims could actually work to exclude people to greater extents. This could be seen, for instance, when Singertree Trust identified staff expenses as acting as barriers to people's genuine engagement with their communities. As I have shown in chapters five and six, people with learning disabilities were significantly reliant on their support workers and other staff members to replicate bonding experiences, such as going to the cinema or bowling. It is true to say that outside of these kinds of support settings, social pursuits tend to be undertaken between friends – people who have selected one another based on authentic relations of some kind (see Putnam & Goss, 2002: p.11, for definitions of 'bonding' social capital). However, as I described with Mark, the young man living at Sanderstead View, if these bonding experiences were not replicated by support workers, Mark tended not to

have the opportunity to experience them at all. This is revealing of how the aspirations of policy to reduce the exclusion people experience by attempting to reduce their dependence on the state may paradoxically serve to increase their exclusion. Perhaps this is also indicative of the need to be more honest about what kinds of inclusion are achievable for people with learning disabilities, because if not, life could be being made worse off for vulnerable people.

### **Emotional labour**

Interestingly, the ways that services can paradoxically increase people's experiences of social exclusion can be seen to be played out in the ethnographic material relating to physical contact. In chapters five and six, I described how people with learning disabilities appeared to express a fundamental need for informal and/or intimate interactions with the people supporting them. However, this kind of support was viewed organisationally as one of the barriers to achieving current policy aims of promoting independent living and community inclusion. This was partly reflected in the way that support staff were directed not to engage in physical contact with the people they supported. Although part of the aim of this strategy was to encourage people to engage with their communities on their own terms, the ethnographic findings showed how some people, like Mark for example, were made worse off by these changes because his support workers were his only life-line to the community. In this sense, it could be argued that the performance individuals in these settings were required to engage in with regard to policy objectives inhibited support workers' and other staff members' ability to respond to the emotional needs of the people they supported. This gives rise to questions relating to the kinds of relationships that should exist between people in support settings in terms of what would be most beneficial for people being supported.

The organisational strategy discussed above, in which Singertree Trust removed staff expenses with the aim of encouraging people's participation in the community, raises these very questions. In attempting to encourage people's participation in the wider community, the option for staff to spend social time with the people they supported was removed. This could be read as part of a wider

move towards professionalising relations between people in support settings as a means of both empowering and protecting them. If there is a professional contractual relationship between people, it is argued that, in addition to being empowered with independent access to the wider community, it is less likely that people will be subject to overbearing support staff who may use their positions of power to abuse and exploit people under their care. Further still, as I pointed out in chapter six, it is recognised that people with learning disabilities can misinterpret friendly gestures for more intimate, even romantic, invitations. Given that individuals with learning disabilities can be vulnerable, it is understandable then that government policy and provider organisations tend to err on the side of risk avoidance and opt to establish professional boundaries with people they support. Indeed, I observed this at Singertree Trust in the rules governing relations between support staff and people with learning disabilities, which stated that these must be grounded in 'professional relationships'.

It is perhaps worth considering the implications of needing to protect against the potential dangers involved in relationships in contexts of care. Regulating relationships in these settings may also speak to the argument some scholars have put forward about the professionalisation of interpersonal relations within all areas of public life. The work of Frank Furedi may be useful to explore ideas about the impact of professionalising interpersonal relations in the context of care. In his book, *Therapy Culture: Cultivating Vulnerability in an Uncertain Age* (2003), Furedi argues that there is an increasing trend towards framing all aspects of social life through emotional experiences, which are increasingly being defined through a therapeutic lens. However, rather than working as a source of empowerment, as is commonly thought, Furedi contends that this therapeutic culture creates the professionalisation of relationships and acts as a way of managing people's perceptions and experiences of their emotional selves. Furedi views this as negative because it imposes a stifling conformity upon people and removes their ability to subjectively and privately experience and understand their emotional selves.

Furedi's examination of emotions and social relations cannot be transferred straightforwardly on to relationships within the context of learning disability social

care. However, the need to mediate interactions in these contexts to ensure that things do not go wrong could be viewed as obstructing the basic human need for intimate relationships to take place in spontaneous ways. This is not to say that social relations within professional caring relations should not be regulated. However, the relationships between people with learning disabilities and their support staff may benefit from being defined in more informal ways. In which, for example, physical contact is not prohibited entirely, but bounded to protect both people with learning disabilities and the people supporting them.

To this end, if – as the findings from this research indicate – a fundamental desire of people with learning disabilities is for an emotional connection with the people who support them, then this type of relationship may be more empowering than the ones that currently exist in this context. Indeed, if we are to think seriously about what would enable people with learning disabilities to lead fulfilling and meaningful lives on their own terms, surely this will need to involve consideration of the emotional bonds they experience with the people who support them. This is particularly pertinent given that beyond this thesis much research has consistently identified that meaningful relational connections with others are much of what is missing in the lives of people with learning disabilities (Richardson & Ritchie, 1989; Firth & Rapley, 1990; Bayley, 1997; Department for Health, 2001; Mirfin-Veitch, 2003; Fitzgerald & Withers, 2013; Azzopardi-Lane & Callus, 2015).

This subject of emotion and professional labour was touched upon in chapter two on pp.51-52 in the section that discussed how moving towards approaching support as a series of task-based activities may have the potential to remove the emotional elements from this work, which can cause staff to objectify the people they support and so impact negatively on the quality of care being delivered. Here, I drew on the work of Isabel Menzies Lyth, whose landmark study of hospital nursing in the 1950s found that there were downsides to the strategies used by hospitals to ensure that nursing productivity was not negatively impacted by the emotional stress nurses experienced from their work. Lyth found that protecting nurses from becoming emotionally involved in their work meant that



they often did not have the means to cope with these stresses over the long term, which led to high staff turn-overs and increased patient recovery times (Menzies, 1960).

Emotional labour has also been explored in detail in Arlie Hochschild's classic study, *The Managed Heart. Commercialization of Human Feeling* (2012). Here, Hochschild looked at the work carried out by airline stewards and found that they were trained to adopt 'management' strategies to suppress their own emotions in order that they could more successfully reassure passengers whilst at work. Hochschild argued that when this 'emotion management' becomes part of a job description, it leads to the commodification of workers' emotions. Similarly to Lyth's hospital nurses, Hochschild described how air stewards' emotions were being managed and suppressed by their employers so that the organisations could continue moving forward and, in some cases, make profits. As did Lyth, Hochschild pointed out the personal costs upon workers who were required to suppress their own emotions as part of their employment role.

Similarly to Lyth and Hochschild, I found that the attempts by service organisations to manage the emotional aspects of people's lives in support settings could be unsuccessful. This was made apparent in the ways that support workers expressed conflict when ignoring or halting the requests for intimacy and care from the people they were supporting. For example, in chapter six when I described how, during a house meeting, support worker David had at first told Mark to stop leaning on my shoulder because it was not "appropriate". After which, he appeared to feel a need to reassure Mark, as he used comforting words to calm Mark down. These types of incidences indicated that support staff were at once aware of their professional expectations whilst also being faced head-on with the human needs of the people in front of them. Indeed, in returning to the ideas put forward earlier in this chapter about the performative effects of policy, this was arguably a confusing and stress inducing performance for both support staff and people with learning disabilities to undergo. For, despite there being defined professional boundaries, in the context of everyday interactions these could be difficult to follow. As such, it could also go some way to explaining the

tensions and conflicts that appeared to be present in the relational dynamics in these settings.

Conversely, however, if we are to think about introducing emotionally-driven support into caring contexts, we will also need to consider how this may impact upon the staff working in these settings. Indeed, thinking about care work from this perspective gives rise to other questions relating to what extent we can expect professionals to provide emotionally-based support, given that this asks a great deal of the people providing it. Within the context of social care, for example, the approach towards professionalising relations could also be a way for support staff to protect themselves from the emotional labour their work involves.

With such considerations in mind, I want to slightly alter the question raised at the beginning of this section regarding what we should expect from relationships in support settings and contend that perhaps we should be asking what kinds of relationships can we expect to exist here? Ultimately, this brings us back to one of the questions posed at the beginning of chapter two, which asked what should/can be the role of the state in this context. If we do accept that people with learning disabilities both seek and require informal, emotionally-driven support from the professionals caring for them, we are left with the question of whether there is a way to determine these relational boundaries so that this does not become disempowering for either one of the parties. Either in the sense that people with learning disabilities are not at risk from being contained and constrained by institutionalised settings, or that too much is not asked of the emotional selves of support staff, who are not being sufficiently supported – both financially and professionally – to take on such immense roles in the lives of vulnerable people.

If then, it is not the place of the state to provide this kind of support to people who require care, whose responsibility is it? Is it that the third sector is better at doing this kind of 'ad hoc' support where people engage with each other in more informal and flexible ways because they possibly tend to be given more freedom to work for their clients, rather than implementing state policies? (Lipsky, 1980).

Some of the ethnographic findings from this doctoral research would support this view that third sector services are less beholden to direction from government, which then allows them to blur the relational boundaries with the people they support. For instance, the way that employment was approached by Steve Connors at the Station Park Café indicated how focusing on imbuing people with value by emphasising their contribution in a symbolic, rather than material, sense was a means by which people with learning disabilities could feel a sense of inclusion, and through this, empowerment.

However, it is also important to point out here that these descriptions of state versus third sector services cannot be used as a blue-print for all other organisations. Indeed, the ethnographic findings presented of the advocacy service, Hear Us, in chapter five from p.139, indicated how a non-state run initiative can be just as vulnerable as their state-run counterparts of attempting to achieve empowerment through abstract, rather than real-life, aspirations. Furthermore, as I described in chapter four on p.119, at the Hilltop Mews day centre I spent time in, which was part of the local authority service, Cambrick, I observed how staff maintained close and informal relationships with the people they supported. As such, this service showed that the emotional needs of people with learning disabilities could be met in state-run care contexts.

Importantly, each approach has what could be described as its failings. Arguably, caring approaches, which could be seen as most common to the third sector, could be viewed as paternalistic and encouraging dependency on organisations, which could also inadvertently cause people to become isolated from different parts of the community. Furthermore, the failure with this support is that, as boundaries become blurred, vulnerable people are more at risk of abuse and neglect. Moreover, we may have to also accept that these kinds of bespoke approaches to supporting people may not be able to function on a big scale, meaning that they may have to remain the domain of small independent services. On the other end of the spectrum, policy objectives which aim to empower people with control over their lives, partly by establishing clear boundaries in support settings, could be viewed as less likely to allow exploitation to occur. However, the emphasis within these objectives of enabling people with learning disabilities

to become as autonomous and self-sufficient as possible is, for many people, an unattainable aspiration. Furthermore, although they are necessary, regulating relations to avoid risks of abuse arguably creates a deficit in interpersonal interactions that has a clear negative impact on both the people providing and receiving support.

Outside of this thesis, these issues relating to how relations in support settings might be best managed were writ large in a news story that broke in February 2014 (Botton Village home 'destroyed' by changes, 2014), that revealed the problems facing the seventy-year-old small farming community of Botton Village in North Yorkshire. The village is part of the charity, Camphill Village Trust that I introduced in chapter one on p.26. This charity is part of a movement which began in the 1940s by escapees from the Nazis. Following the atrocities of the Second World War, they wanted to emphasise the value of all human life and inspire a vision of social solidarity by showing that people with learning disabilities could live meaningful lives. A crucial aspect of this involves people with learning disabilities working and living alongside the people who support them. To realise this vision, rather than working as conventional employees, staff are known as co-workers and are employed on a voluntary basis, in exchange for free accommodation, food and expenses. For Camphill, this distinction is crucial as it defines relationships in terms of love rather than a contractual obligation (Camphill Village Trust, 2017b).

However, in 2014 HM Revenue and Customs (HMRC) declared that tax arrangements at Botton were not transparent enough, and because of this, the co-workers would have to become conventional employees. For Botton, the implications of this decision were far reaching, as working ordinary shifts and receiving a wage meant that co-workers would no longer be able to live with the people they were supporting. Although some co-workers and people with learning disabilities at Botton were happy to accept these changes, for others this was a direct attack on their very way of life.

On the surface, the demands for Botton to modernise relate to the need to better regulate labour time in the care sector. However, it is worth considering that these

demands came in the wake of the 2011 Winterbourne View scandal that I described at the beginning of this thesis, in which the BBC current affairs programme, *Panorama*, exposed the terrible abuse taking place at an assessment and treatment unit for people with learning disabilities in Bristol. The realisation that such abuses were happening in English services and in the 21<sup>st</sup> century shook the social care sector to its very core, and both the government and the Care Quality Commission (CQC) were obviously deeply sensitive about not letting this happen again.

In my view, the story of Botton runs to the heart of debates within this doctoral thesis, as well as more broadly about how we define care in the 21<sup>st</sup> century. Clearly, the exposure of Winterbourne View has left a desire for better regulation in state-governed sectors. However, should the response to this be to remove those remaining aspects from social care support that cannot be regulated or predicted, such as informal and intimate relations? Those types of relations that Botton prides itself on aiming to achieve. Vulnerable people, such as people with learning disabilities, need support throughout their lives, and perhaps we must accept that the type of labour involved in this support will always be bound up in social relations that we cannot fully control, despite our benevolent desire to do so. There will always be a potential for these relations to be undermined, and at worst exploited.

In returning to Frank Furedi's (2003) arguments presented earlier in this section, which contend that, by funnelling our emotional experiences through a lens of conformity we may just be losing something of ourselves that is so crucial to what it means to be human. In the context of the lives of people with learning disabilities, perhaps we need to accept there will always be a trade-off, but that this is a legitimate one if it means that people are given the opportunity to experience meaningful relations with others. However, despite the problems that this thesis has described regarding the implementation of policy objectives within social care support, it is also necessary to outline out that policy itself does not make relations in these settings inherently problematic. Rather, it is the relations themselves that are inherently problematic, which means that boundaries around these relations will always be complex and opaque. Indeed, in this sense, the

nature of care could be an ongoing exploration in attempts to assess and reassess these boundaries, and in doing so, what it means to care and to be cared for.

### **The flaws of liberal and social democratic politics for people with learning disabilities**

In chapter one, I described the development of learning disability policy objectives from the mid part of the 20<sup>th</sup> century through to the present day, describing how changing attitudes towards people with learning disabilities have been shaped by wider movements. The result of these developments is what we see in the shape of contemporary social care policy – along with the duty of care to protect vulnerable people, there is a complex amalgamation of values derived from a range of social, political and economic stances that have come to shape and define ideas about how people with learning disabilities might be best enabled to live fulfilling and meaningful lives.

Through this thesis, I have attempted to critique and challenge the ways that people with learning disabilities have been constructed through various kinds of identities. For instance, using the market to regulate the social relations that make up the support provided to people with learning disabilities has found to be problematic. The attempt to empower people as consumers is a troubling concept given the fact that the nature of their condition means that, even if they were to take on their consumer powers, it would be with support from others, which would then serve to compromise the liberal philosophical values underpinning this interpretation of individual freedom.

However, the social democratic approach to promoting the autonomy of people with learning disabilities has also found to be wanting. The idea that the lives of people with learning disabilities can be improved through equality of outcome interventions – by providing them with equal access to institutions and social relations – has failed to take account of the ways in which people's cognitive impairments materially limit their ability to exist on the same footing as non-disabled people.

Conceiving of these various forms of freedom for people with learning disabilities are essentially attempts to construct identities and social relations in ways that will enable them to live what might be called the good life (Johnson, 2013), which I touched on in the introduction of this thesis from p.12. Philosophical conceptions of the good life are complex and varied (Carel, 2017) and exploring this in full has been beyond the scope of this thesis. However, I have attempted to point towards the philosophical roots of these ideas to show how they have influenced and shaped policy governing care and support provided to people with learning disabilities in the UK. Indeed, the notion of a good life from an Anglo-American and European philosophical perspective nicely encapsulates the objectives of contemporary learning disability social care policy. In this sense, these objectives can be viewed as value-based in that they favour those values relating to empowerment in particular kinds of self-determined ways. However, conceiving of individual freedom through such heavily cognitive forms, as is required by these philosophical foundations of the good life, could be considered as problematic for some individuals, such as people with learning disabilities. This raises the question of how people with learning disabilities can fit into these processes, which require levels of reason and reflection sophisticated enough for 'good' decision-making to take place.

In chapter two from p.71, the problematics of this were discussed through Marcus Redley and Darin Weinberg's ethnographic study of the workings of the self-advocacy group, the Parliament for People with Learning Disabilities (PPLD) (Redley & Weinberg, 2007). Here, Redley and Weinberg point out the contradictions in the idea that people who receive state support because they are intellectually impaired could be empowered through a model of liberal citizenship that is predicated on the ability of participants to independently engage in reasoned and reflective debate. Elsewhere, through the theoretical lens of Jurgen Habermas's work on democratic empowerment and citizenship, Weinberg has explored the problems that ensue when people with learning disabilities are framed within a form of individual empowerment rooted in liberal democratic political theory. In this analysis, Weinberg describes how, given the material nature of learning disability, even in principle, it is difficult to determine how the Habermasian argument that people's individual rights are secured through their

ability to exercise those rights within 'the democratic legislative process' could be satisfied with this group of individuals (Weinberg, 2007: p.79).

Elsewhere, in her examination of the UN Convention of the Rights of Persons with Disabilities (CRPD), Kelley Johnson (2013) showed how these very ideas of active citizenship pointed out by Weinberg are expressed as necessary for enabling people with learning disabilities to become citizens: 'the CRPD argues not only for the rights of citizens to be active in their own lives but that agency as citizens is integral to the actual implementation of the CRPD' (p.226). In this way, Johnson illustrates how this framework continues to promote 'a specific rights model which reflects prevailing views of a good life as one of independence and the exercise of reason' (pp.223-224). Furthermore, she says, the stance towards removing the barriers in society that inhibit people's involvement indicates how it is heavily rooted in the social model of disability, which also centralises individual rights and autonomy. Johnson acknowledges that the CRPD 'is an important step forward' for people with disabilities, as it brings to the fore rights of autonomy and equality that are required for society to become more ethical in relation to these groups. Yet, she goes on to ask, 'what of the people who cannot exercise the kind of autonomy and action promoted within the CRPD? ... for example, some people with learning disabilities' (p.226).

Although current legislative powers acknowledge that rational decision-making is problematic for people with learning disabilities, they also appear to fail to acknowledge the analysis that people's cognitive impairments exclude them from meaningful participation in these processes. Indeed, as I described in chapter one on p.42, the Mental Capacity Act 2005 (MCA) has sought to ensure decision-making capabilities of people with learning disabilities are preserved in decisions relating to their health and social care. The vital aspects of this hold that capacity must be viewed as context and decision specific, and just because a decision is considered to be unwise by others, does not necessarily diminish the legitimacy of the decision for the person wishing to take it. These legislative powers can themselves be traced to social democratic political concepts about equality and the drive towards levelling to ensure that people are positioned on the same footing. Despite the clear moral intent behind such aspirations, these kinds of



levelling processes are arguably highly problematic when transferred on to the real lives of people with learning disabilities.

Indeed, the ethnographic findings from my doctoral research indicate problems with the assertion that abstract ideas about capacity can be necessarily translated into the lives of people with learning disabilities. This was illustrated, for example, in the findings when I described the young men at Sanderstead View, Joey and Sam, getting into trouble. The issue here is that so much of determining whether people have capacity relies on the verbal responses they provide to people around them. As I discussed in chapter six on pp.180-181, whilst spending time with Joey and Sam, as well as other people with learning disabilities, I found that it could be difficult to determine whether they were expressing their true feelings and thoughts, or whether they were mediating their responses towards their support staff, either in attempt to satisfy the expectations of staff, or to evoke a desired response, such as sympathy, from staff. An argument could be made here, as it has been made elsewhere (Kittay, 2011), of the relational character of capacity. Either way, this susceptibility to others indicated to me, the fragility of the young men's ability for autonomous, self-determined and rational thought processing under the conditions set out in the MCA. Thus, given that there were blurred lines in determining the abilities of the young men, it was arguably unclear as to whether they were aware of the consequences of the decisions they were making.

It could be argued here that the ability of the young men to alter their responses to support staff for their own gain indicated an awareness, on some level, of an ability to manipulate the behaviour of others. Indeed, this could perhaps be seen to accord with the idea that the young men were exercising power over support staff, for example when they would refuse to engage in domestic responsibilities. However, rather than self-determined and rationally-based, I observed how these manipulations were indicative of more general frustrations experienced by the young men brought about by their experience of being at once aware of what could be possible in human life and living with a sense that this kind of life would remain ever elusive to them. This sense of the difficulties of living an opaque

existence between levels of awareness was well conveyed in the words of Mark's mother, April, who described how:

"I don't think he can make the choices what he wants. He's not like an adult like us, we know what we're gonna do each day, Mark don't. And, I think he finds days when he gets really frustrated sometimes" (April Whyatt, interview, 7<sup>th</sup> February 2015).

In chapter two on p.65, and earlier in this chapter on pp.198-199, I introduced and discussed Erving Goffman's concept of 'passing' (1963) as a way of illustrating how some people with learning disabilities may attempt to conceal their disabilities to be accepted by the rest of society. For the young men with learning disabilities with whom I spent time, I sensed a palpable desire on their part to be able to 'pass', which is also conveyed well in the quote above from April, Mark Whyatt's mother, when she described how he would become "frustrated". Perhaps this was also reflected through certain rebellious behaviours the young men engaged in, such as refusing to do domestic tasks, shoplifting and not returning home at the time of their agreed curfew. In breaking these rules, the young men may have felt that they were resisting against the structures of their social support, structures that were so influential in defining their difference in relation to others. As such, through these resisting behaviours, the young men may have been seeking to grasp moments of feeling 'normal', and of living what they may have perceived to be a 'normal' life outside the boundaries of their support.

In returning to Darin Weinberg's exploration of Habermas's notion of democratic empowerment and citizenship, he voices the dangers of accrediting people with learning disabilities with too little capacity to understand the implications of their actions. Weinberg argues that, for the betterment of social life it is necessary to consider others as possessing a greater rather than lesser ability for rational behaviour. Yet, he states, it is also vital that these principles upholding individual rationality are not perceived as incontestable. For, as he points out, the historical evidence in policy-making governing mental health care shows the damage this can do:

‘History has shown rather convincingly that injustices flow not only from our failures to adequately respect the intrinsic rationality, autonomy, and voice of those we do not immediately understand. It has also flowed quite catastrophically from our unwarranted and dogmatic faith in that rationality, autonomy, and voice. As most of us now accept, the deinstitutionalization of people with mental health problems was not the unmitigated success some promised it would be. And this was not only due to a failure to adequately empower former inpatients. It was also due to our overestimation of their capacities to look after themselves independently (Weinberg, 2007: p.82).

Despite the historical evidence that shows the downsides to overestimating people’s ability to successfully self-govern, to provide a more balanced argument, it is also well worth reiterating the first point made by Weinberg, of the importance of accrediting people with more rather than less ability to act in a rational manner. Certainly, this is a crucial aspect of both improving and fulfilling the lives of people with learning disabilities, many of whom have been constrained and contained within institutionalised settings. However, to do this well, surely decisions made should be grounded in rigorous empirical evidence of what might be possible to achieve as opposed to abstract notions of self-sufficiency, rationality and equality that cannot necessarily be transposed on to people’s lives.

As I have pointed out throughout this thesis, it can be almost impossible to make definitive and generalised statements about the lives of people with learning disabilities in ways that accurately reflect their lives. Indeed, this is also the case when we are considering people’s potential to develop and flourish. However, even when people are provided with education and environmental settings that enable them to flourish, it is an unavoidable truth that people with learning disabilities are cognitively impaired. To varying degrees, this will hinder their ability to fully comprehend the complexities of social life, including rights and responsibilities as they are set out in laws and policy. Importantly, some of the people with learning disabilities I spent time with during my research were considered to be among the more able individuals. However, if, as my findings

have shown, taking on the kinds of obligations and responsibilities that accompany aspirations promoted through policy tended to be too much of a challenge for these individuals, it is difficult to conceive of how these aspirations might work successfully in the lives of people who are more severely disabled.

In pointing out the ways in which the UN Convention similarly categorises people with learning disabilities into a particular type of human mould, Kelley Johnson argues that there is a need for conceptions of the good life to be more fluid and expansive than simply through values of independence and the ability to reason and reflect (Johnson, 2013). Johnson contends that, although these values may well support some disabled people in leading fulfilling lives, they do not necessarily work for other people, who may value or benefit from social relations that focus on care and interdependence. Here, Johnson is not alone in calling for this expansion of values in determining what it means to live well. She situates her argument in the context of debates which I touched on in chapter two on pp.58-59, in which scholars have drawn upon ethics of care and relational dependency as ways of thinking about how to relate to people with learning disabilities outside of the traditional liberal and social democratic concepts of autonomy. In illustrating the importance of care and dependency for human relationships, Johnson goes on to quote the work of Eva Kittay & Ellen Feder (2002), who state that:

‘An ethics of care may be one way to understand the moral commitments and relations that arise among the persons unequally positioned in relations of dependency. Yet the harms and vulnerabilities that accrue to those who do dependency work may also reveal a limitation in care ethics and suggest the need to reintegrate care into a paradigm of not just moral and political arrangements, but one that acknowledges those dependencies that call for care and support. Such a paradigm is not yet available’ (cited in Johnson, 2013: p.227).

In this extract, Kittay and Feder indicate the deficit of care ethics as being the negative impact this work holds for those delivering it and receiving it. Their

response is to reconstitute a just concept of the processes of care in order that the acts of *doing* care and *being* dependent do not subordinate those involved. A few paragraphs on in their text, Kittay and Feder ask the question, 'how can we deal justly with the demands of dependencies that constitute inevitable facts of human existence, so that we avoid domination and subordination with respect to care and dependency' (Kittay & Feder, 2002: p.3). In asking this question, their aim is to find a 'just social order in which we all can find a meaningful sense of freedom grounded in human dependence' (p.3).

When thinking about this in relation to the main thesis of this doctoral research, the argument that people would benefit from a more expansive notion of what it means to live well, to live a good life, has been evident in the ethnographic findings presented here. In this, it has been made clear that the dominant conception of a good life, as one defined by the presence of autonomous, self-sufficient agency and reasoned thinking, should not necessarily be favoured over human needs for care and emotional connections. Clearly too, the argument made by Kittay and Feder, of deconstructing domination and subordination through just moral and political arrangements is a compelling one. Yet it is at this point that my thesis departs from this notion of the emancipatory potential of relationality. This is on the grounds that, similarly to the dominant ideals of autonomy that the care ethics approach is pitting itself against, the desire of deconstructing an unjust structure in order to reconstruct a just one seems to me to be repeating the mistakes of a social democratic vision of equality, in which the material reality of people's conditions and the impact this has on lived experiences are ignored in favour of an idealised vision of how things could be rather than how in fact they are. If we are seeking to construct honest relations between people with learning disabilities and the people supporting them, I believe these relations should be defined by their inequality rather than their equality.

### **Chapter conclusion: implications for policy and practice**

There is a tension here that continues to be unresolved: between abstract ideals and the lived realities of people with learning disabilities and support workers. In

my research, I found that people with learning disabilities were often not able to take on the rights and responsibilities that accompany the various identities constructed for them through policy. Due to the limits their condition placed on them, ideals of independent decision-making and community inclusion were not possible for many people to achieve in the ways that policy describes. Indeed, I found that without staff support people with learning disabilities tended to be unable to do many things.

Importantly, as well as being played out in a physical sense, such as needing support to go to the shops and organise general aspects of their lives, this dependence was also played out in an emotional sense, as people with learning disabilities would seek comfort and support from staff, for example, through attempting to hug them or to hold their hand. However, the abstract ideas around independence and community inclusion were so pervasive that people in these contexts felt compelled to engage in a performance through which these ideals were seen to be enacted. This then served to mask some of the emotional needs of people with learning disabilities, such as the need for physical contact.

With a view to illustrating the tensions that emerge out of the disparities between abstract ideals and people's lived experiences, it will be helpful to return to the issue of emotional labour discussed earlier in this chapter from p.201. Within the services I spent time, rules regarding physical contact accorded with the primary aims of contemporary social care, that of to ensure the promotion of autonomy for people in receipt of support. More implicitly, however, these rules were also there to protect both people with learning disabilities and the people supporting them from being taken advantage of in what can be vulnerable moments in the delivery and receipt of care. For example, a person with learning disabilities may feel they are being exploited or abused, or a member of staff may have observed them being treated inappropriately; and vice versa, a support worker may feel they themselves have experienced, or have witnessed another member of staff subjected to inappropriate treatment by people they support. Part of the idea behind these formal rules then is to govern what kinds of interactions are acceptable in the context of care in the hope that there is less chance for confusion or coercion to occur.

Despite this, however, it appeared that emotional labour was an inherent part of the relational dynamics between people with learning disabilities and their support workers. I observed how support workers appeared to use rules governing physical contact to protect themselves personally from the emotional labour that was present in their interactions with the people they supported, such as during requests by people with learning disabilities for hugs or to hold hands. Furthermore, people with learning disabilities themselves appeared to use these requests for physical contact and reassurance as ways of gaining power in the moment, as it was often difficult for support workers to deny entirely the requests from the people they were supporting. This issue relating to the emotional aspects of people's interactions raises questions about how support is – or can be – defined in these settings, and how much emotionally we can expect staff to provide to people they care for in a professional context.

The complexities surrounding emotions within these care dynamics are not acknowledged in government policy, which instead promotes independence and, where possible, for people with learning disabilities to be less dependent on support workers. Nor is it acknowledged in organisational rules, which attempt to manage accountability by professionalising the relational dynamics between people with learning disabilities and support workers. This is indicative of how both the state and the market are failing to recognise – or acknowledge – some of the real needs of people with learning disabilities. In differing ways, both the state and the market attempt to empower people with learning disabilities with individual freedom, but this continues to fail to incorporate the need for emotional connections that are central to caring relations.

Perhaps then, this is about reimagining what care means within the context of the state and the market. What this relationship will look like in everyday care relations will depend on what is possible for people in this context. But, I believe that it is relationships between people with learning disabilities and their support staff that need to come first, rather than abstract notions of social, political and economic freedom. In this sense, this thesis does resonate with the work of others who have pinpointed social relations as key to improving the lives of people with learning disabilities. Unlike many others, however, I believe that we need to put

people's disabilities at the centre of these relations and accept that there will always be imbalances of power in this. It is through being honest about the lived experience of disability that honest relations, built on genuine need, can be formed. Masking people's differences rather than embracing them stops people from being seen for who they really are, which hinders the emancipatory potential of human relationships.

It might be worthwhile here to end this chapter by returning to the cases of failings in learning disability services that I described at the beginning of this thesis. This is not at all to suggest that further consideration of people's material condition might mean that all abuse and neglect will be permanently wiped out from social care support. Again, as I have pointed out, it is not policy that imputes inherent problems into relations of care; these relations are in and of themselves inherently problematic. However, it may be worth considering the ways that people are currently being constructed through policy objectives and how this may be making it harder for people to flourish under these conditions. Indeed, the quote from Jean-Paul Sartre provided at the start of this chapter illustrates well the temptation to manage people into a certain way of being, which appears almost to be out of fear of what will happen if they elude this. In the case of people with learning disabilities, perhaps this is about facing up to the unavoidable truth that some things will remain unequal. Yet, being brave enough to accept this deficit may lay the ground for the kinds of genuine relationships that enable people to flourish in their lives.



## Chapter eight

### Conclusion

*“My friends from the prison, they ask unto me, ‘how good, how good does it feel to be free?’ And I answer them most mysteriously, ‘are birds free from the chains of the skyway?’” (Bob Dylan, *Ballad in Plain D*, 1964).*

Through this thesis, I have sought to explore how policy objectives that aim to empower people with learning disabilities to become autonomous in various ways, whilst also protecting them from harm, have been enacted in the context of everyday support. More broadly, this can be described as an exploration of situated experiences of care and the way that this sits within a landscape of values determining particular kinds of care practices to be acceptable. To this end, this thesis has engaged with debates about how care and support might be provided to people in ways that best improve their lives. Yet, these explorations have wider implications, as seeking to explore how a fulfilling life might be achieved for people with learning disabilities is intimately connected with conceptions of what it means to be human more generally.

The political rhetoric governing social care support has emerged out of a set of social, political and economic ideas that, within policy as well as other areas of social discourse, have come to construct a range of identities of what it means to live well as a person with learning disabilities. In everyday terms, these identities have been translated as enabling people to become independent decision-makers with equal access to their communities through, for example, housing, employment and relationships. Despite the benevolence underlying these aspirations, however, the ethnographic findings from this doctoral research indicate that incorporating these identities into the lives of people with learning disabilities tended to be problematic. For many people, their intellectual – and for

some physical – impairments acted as a barrier to this, and people experienced great difficulties in independently harnessing their own agency. In fact, rather than seeking independence from the people providing them support, it was often the case that people with learning disabilities sought to be empowered through the relations and emotional connectedness with their support workers and other staff. In this sense, the social, political and economic constructs of learning disability clashed with people's lived experiences of this.

Following this, the findings from this research indicate a disjunction between policy objectives promoting particular kinds of independence and inclusion with what people with learning disabilities both wanted and were capable of achieving. Simply assigning people with learning disabilities certain kinds of identities was not enough to truly empower them because they tended not to have the ability to harness and realise their given power in meaningful ways. Despite this disjunction, however, the values that underpin policy objectives were so pervasive that people with learning disabilities and their support workers and other staff were often compelled to partake in a performance whereby they attempted to enact these policy objectives. In turn, this perpetuated the notion that these were attainable goals for people with learning disabilities. By engaging in a pretence that people's disabilities did not hinder their ability to function as self-sufficient and autonomous agents was to mask the reality that there were material differences between people with learning disabilities and people who do not experience this condition. This pressure to conform to a particular type of empowerment had implications for the ability of people with learning disabilities and support workers to relate to each other in ways that enabled people's needs to be met.

It is without doubt that the intent behind the liberal and social democratic principles that try to achieve individual freedom, societal equality and fairness is benevolent. Yet, to ignore that there are aspects of the experiential reality to impairment that cannot be overcome could be described as more of a disservice to people with learning disabilities than admitting that they are not the same as others. Masking people's differences, rather than embracing them, arguably undermines the ability for people to see each other for who they truly are, which

ultimately distorts the emancipatory potential of human relationships. Crucially, this is not to say that we cannot do anything to improve the quality of people's lives, but rather it is that the current aspirations associated with this improvement tend to be too tightly defined within, often conflicting, individualistic terms, and as a result can cause alienating and damaging effects for the people involved.

In turn, this raises questions relating to whether we should be promoting the kinds of social, political and economically driven identities for people with learning disabilities that emphasise various forms of individual freedom over caring relations and paternal security. If indeed, as others have, we do accept there are caveats in liberal and social democratic notions of freedom for people with learning disabilities, any attempts to think differently must then involve deep and existential thinking about what it actually means to be human. If we are to achieve this in any meaningful way, the perceived negative effects of compromising autonomy may have to be thought of differently. This could relate, for example, to the issue of how we approach and negotiate freedom for people with learning disabilities – rather than preparing them for the 'real' world, perhaps we should consider what a freedom that is more bounded and protective might look like, a progressive paternalism that promotes choice within caring and protective relationships. Within the context of everyday caring practices, this is about the relationship between empowerment and paternalism and how these might be worked out together, which would involve incorporating acceptance of people's impairments into this relationship.

Yet, within this notion of a progressive paternalism the limits to what can be achieved must be acknowledged. The nature of the professional support context, in which most people with learning disabilities tend to experience much of their social relations with others, are constrained by the potential for relations within these contexts to become overbearing and so disempowering for people with learning disabilities. Furthermore, suggesting the possibility that support staff working in this field might be asked to provide an emotional part of themselves in their everyday work must be considered within the context of how this professional role is valued, both socially and economically. In this sense, the

aspiration to improve the lives of people with learning disabilities also hangs on what we can reasonably expect from the people supporting them.

This brings us back to the statement made in the opening paragraph of this chapter, which suggested that the implications of understanding everyday social relations in learning disability support settings extend beyond this context towards very conceptions of what it means to be human. Indeed, the popular adage goes that a society can be measured by how well it treats its most vulnerable members. However, I want to turn this on its head and suggest that in fact, UK-based learning disability policy is more revealing of how society would like itself to be perceived. In this sense, our inability to comprehend and to discuss alternative notions of a good life outside of those which are defined by dominant social, political and economic constructs of freedom, as well as the philosophies that underpin these, means that comprehending what this might be for people with learning disabilities remains elusive. As the words of Bob Dylan at the beginning of this chapter perfectly illustrate, all life is bounded, no matter how much this may appear not to be the case. Thus, the first aim here then is to break through this presentation of an idealised version of humanity that is arguably unattainable for us all, not least for people with learning disabilities.

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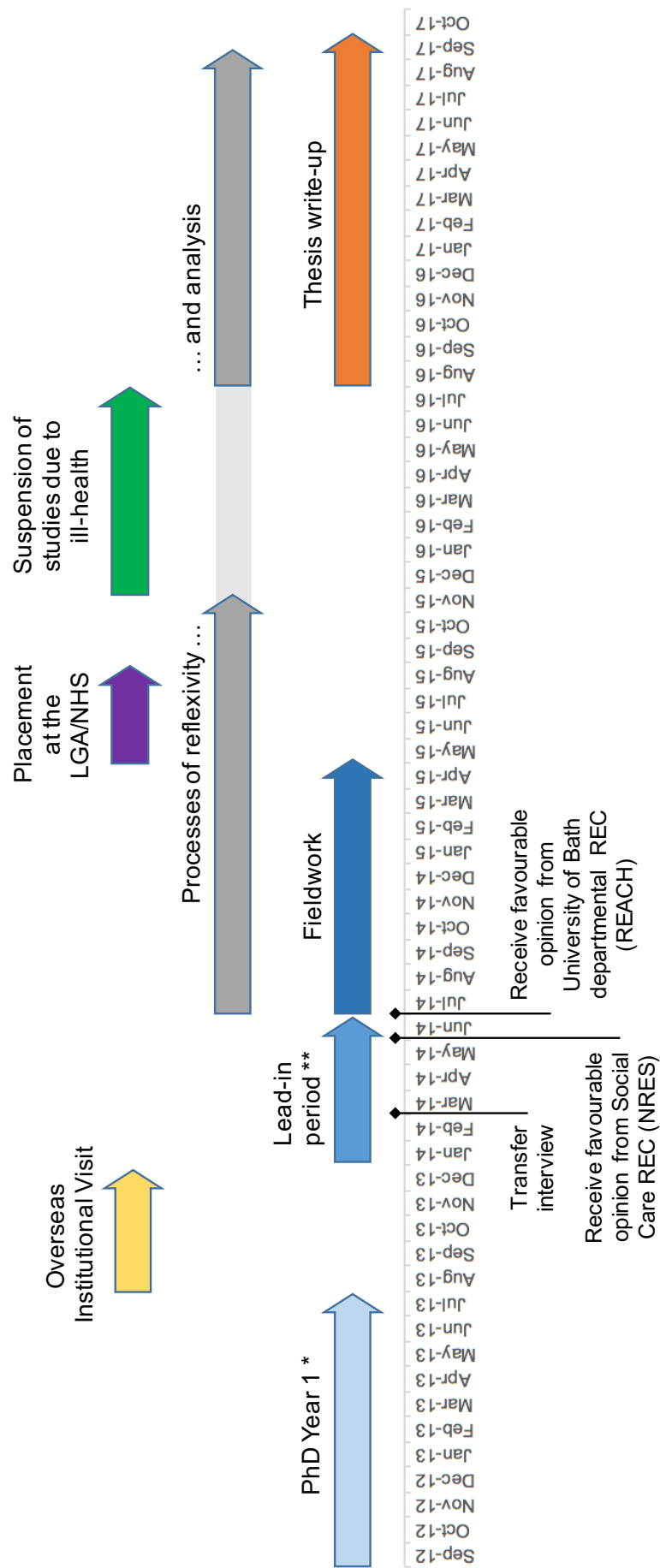


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## **Appendices**

NB: for anonymity purposes, some of the following information has been redacted.





**Figure A.** Timeline of doctoral research.

\* PhD Year 1: this year consisted of reading the literature, refining the research question and preparing for the transfer interview.

\*\* Lead-in period: this corresponds to the locating and contacting of field sites.

## APPENDIX 1

**Table A.** Time spent in the field.

<b>Date</b>	<b>Number of meetings</b>	<b>Number of visits /month</b>	<b>Accumulated fieldwork hours /month <sup>§</sup></b>
January-July 2014 (lead-in period)	8		
July 2014		11	88
August 2014		14	115
September 2014		18	140
October 2014		18	119
November 2014		18	117
December 2014		11	91
January 2015		9	60
February 2015		7	32
March 2015		7	28
April 2015		2	8
<b>TOTAL</b>		<b>115</b>	<b>798</b>

<sup>§</sup> fieldwork hours rounded to the nearest hour.

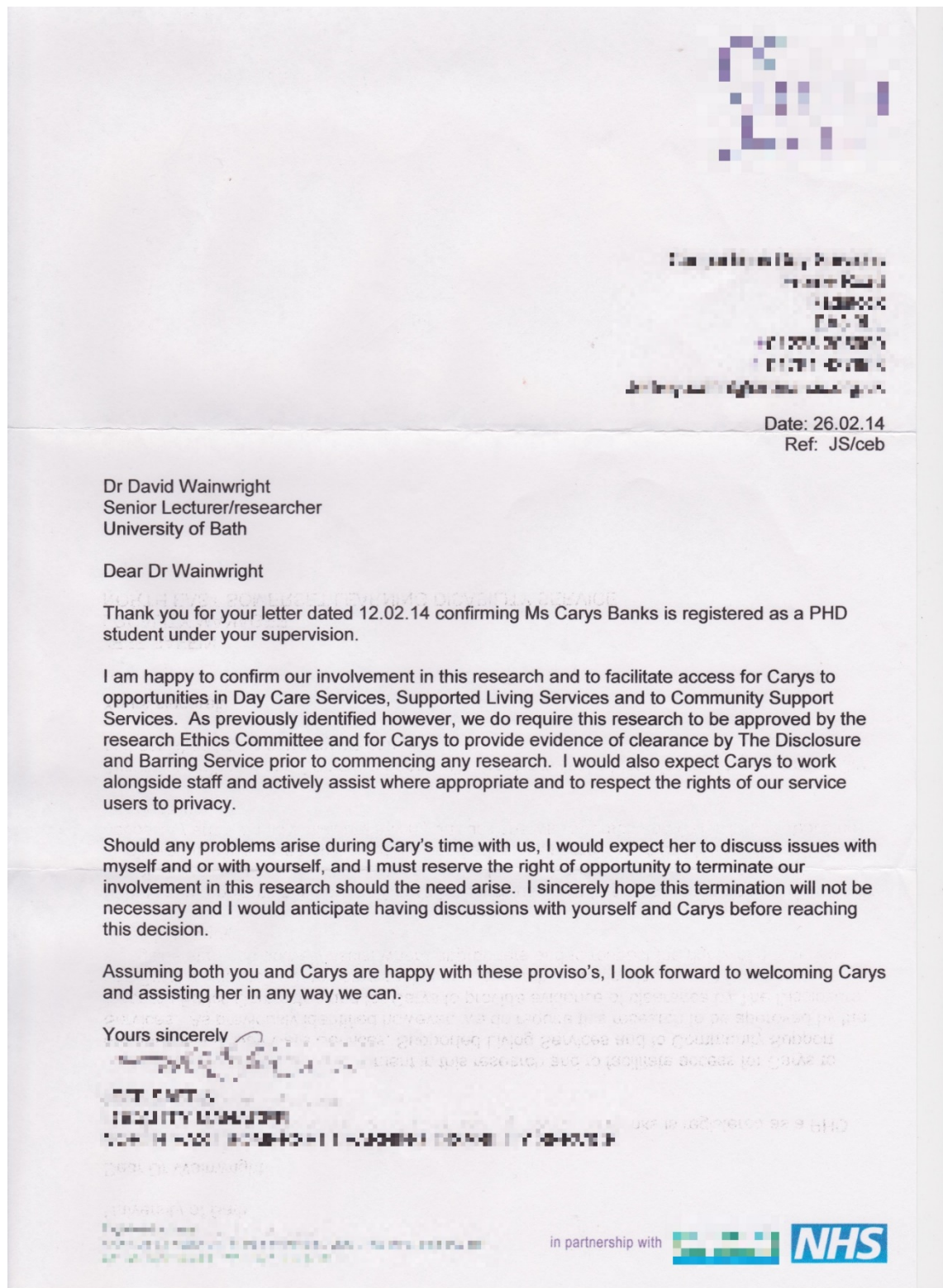
(in addition to these visits, there was additional contact, including formal interviews, telephone calls, emails and letters).

Acceptance letter, Singertree Trust.

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## APPENDIX 2

Acceptance letter, Cambrick.



## **APPENDIX 3**

- Participant information sheet (PIS) for people with learning disabilities.
- Consent form for people with learning disabilities.
  
- Participant information sheet (PIS) for support workers/other staff.
- Consent form for support workers/other staff.



## **Participant information sheet for people with learning disabilities**

### **Understanding care and support for people with learning disabilities**



**Please take time to read this. You can ask someone who supports you to read the information.**

## ***Who am I?***



My name is Carys, and I am a student at the University of Bath in Somerset.

## ***What is this study about?***

I would like you to take part in a study about support provided to people with learning disabilities.

## ***Why have I been asked to take part?***



I am asking you to take part because you receive support, and I would like to ask you about this.

## ***What will happen if I take part?***



I will ask you to sign a form saying that you understand what



will happen and that you would like to take part.

You can take 2 weeks to decide.

You can speak to someone you trust about this.

To make sure that you still want to take part, even after the study has begun, I will keep asking you if you are happy to be involved until the study has finished.

You are free to leave the study at any time.

You will only be included in the study if you agree to take part.

### ***Taking part in the project:***

I will spend time with you when you are receiving support.

I will visit you at your home and come with you when you take part in your daily activities.

I will visit you about 3 times per week and for quite a long time, about 9 months.

You don't have to speak with me every time I visit.

Before I start the project, I must be told that I can do it. This makes sure that the project is safe for you. If you want to, I will also ask you to take part in an interview so that I can ask you directly about your experiences of receiving support. So that I can remember what you have said I may record the interview.



### ***What are the benefits?***



I hope that this study will show us more about how you receive support as well as how you would prefer to be supported to do things like activities at home or during the day.

### ***What are the risks?***



Thinking about some things might be upsetting for you. If this happens and you want to leave the study we can talk about it. You can stop doing the study anytime you want and you don't need to tell me why.

### ***Do I have to take part?***

No, it is up to you whether you would like to take part.

You can change your mind at any time about being in the study.

Leaving the study will not affect anything about the care and support you receive.

## ***What will happen with the findings?***



All information that I collect about you will be kept private, and stored at The University of Bath.

I will change your name and the names of people who support you and the organisation that provides your support.

No one will be able to tell that the information is about you.

Everything you tell me is private unless you tell me something that could mean you or someone else is at risk of harm. I would discuss this with you before telling anyone else.



At the end of the study I will write a report about what I have found. The results of the study will be published in special magazines for researchers, and I will give presentations at conferences.

## ***Who is organising and funding the study?***

I am organising this study and it is part of a project I am doing at the University of Bath, and which is funded by an organisation called The Economic Social Research Council (ESRC).

## *What if I have any questions, problems or complaints?*


You can contact me directly, or ask someone you know to contact me:

### **Carys Banks**



Department for Health  
University of Bath  
BA2 7PD  
01225 385 833



  
c.a.banks@bath.ac.uk

Or, if you want to speak to someone else, you can also contact my supervisors:

### **Dr. David Wainwright (project supervisor)**



Department for Health  
University of Bath  
BA2 7PD  
01225 38 5477



d.wainwright@bath.ac.uk

### **Dr. Rachael Gooberman-Hill (project supervisor)**



School of Clinical Sciences  
University of Bristol  
BS10 5NB  
0117 414 7845



r.gooberman-hill@bristol.ac.uk

**Thank you for considering taking part in my research  
and taking time to read this information sheet.**

## CONSENT FORM FOR PEOPLE WITH LEARNING DISABILITIES

### *Understanding care and support for people with learning disabilities*

Thank you for reading the information sheet. If you understand it, you now need to decide whether you would like to take part in the project.

**Please put a circle around: NO or YES**

1. I have decided that I would like to take part in the project with Carys: **NO / YES**
  
2. I know that I can say yes or no. It is up to me whether I take part: **NO / YES**
  
3. I know that Carys may show some other people at her university what she writes about me, but she will change my name and the organisation supporting me so no one will know it is me: **NO / YES**

4. I understand that Carys might keep some information she has written about me, but no one will know that it is me, and the information will be kept safe: **NO / YES**

5. I know that if I don't want to be part of the project anymore I can tell Carys not to keep what she writes about me: **NO / YES**

6. I know that Carys may use a voice recorder to record what we say, but I do not have to agree to this: **NO / YES**

7. I know that Carys might use what she writes about me when she writes in magazines and talks at conferences, but no one will know it is me: **NO / YES**

If you have any questions, please ask me before you decide whether to take part. You will be given a copy of this consent form to keep.

Name of participant:

Date:

---

Signature

Name of researcher:

Date:

---

Signature

***For use when oral and non-verbal consent is given:***

Confirmation that oral or non-verbal consent has been witnessed

Researcher:

Print name:

*(also signed and dated by support worker if requested by adult with learning disability).*

Date:

When completed: one copy for participant, one copy for Carys.

## Understanding care and support for people with learning disabilities

### Participant information sheet for support workers/other staff

#### *Who am I?*



You are being invited to take part in a study being undertaken by myself, Carys Banks, a PhD student at the University of Bath.

Before deciding whether to take part, you may wish to know why the study is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information. Again, take time to decide whether you wish to take part. Thank you for reading this.

***Part One** tells you the purpose of the study and what will happen if you take part. **Part Two** gives you more detailed information about the conduct of the study.*



## ***Part One***

### ***What is this study?***

As part of my university studies I am completing a study that aims to learn more about the services people with learning disabilities receive. I have chosen to do this because there is not much understood about the everyday experiences of people with learning disabilities and those who support them. I hope that by doing this study, I might, in a small way, help government and local services to improve the care and support they provide to people with learning disabilities.

### ***Why have I been chosen?***

I have asked you to participate in this study because you are a support worker/other staff member, and as part of this role, you provide support to people with learning disabilities.

### ***Do I have to take part?***

Participation in my study is completely voluntary and it is up to you to decide whether to take part. If you decide not to, I will completely respect your decision. If you decide to take part, you are still free to withdraw at any time without giving a reason. During the study, I will regularly ask you to think about whether you are still happy to take part and happy for me to collect information about you, and whether you still agree to me keeping the information that I have already collected.

### ***What will happen if I do take part in the study?***

After you have read this information sheet, you can think for two weeks about whether you want to take part. During this time, you can consult with others if you wish. If after this, you do decide to take part, I will ask you to sign a consent form, which shows that you have formally agreed to take part. If you do not agree to take part you will not be included in the study.

If you agree to take part in the study, I will then ask selected service users who you regularly support to also take part. This is so that I can spend time with you and service users at the same time. If you do not agree to take part, I will not ask the people you regularly support to take part.

If you have agreed, I will begin to spend time with you, other support workers and people with learning disabilities you support. I would like to spend time in both people's homes and with them during daytime activities so that I am able to get a rounded view of all the support people receive.

As well as spending time with you, other support workers and people with learning disabilities, I may also ask if you would like to take part in an interview. This is not

an assessment, but just a way for me to find out more about your own experiences of providing support to people with learning disabilities. If you don't mind I will ask to record the interview with a voice recorder. This is so that I can remember what we discuss and record it in written format. I will be the only person to ever listen to the recording.

Altogether, I hope that my study will last for about 9 months, and during that time, I expect to visit people providing and receiving support about 3 times per week, but I do not expect you to spend all that time with me, as I will also be spending time with other people.

### ***What are the possible benefits and/or risks of taking part?***

I hope that the findings from this study will provide a better understanding of the ways that social care support is provided to people with learning disabilities, which may help to improve future service delivery in this area.

Although this study is not an assessment of your employment performance, you may find it difficult to think about and/or discuss some aspects of what you do. If at any time, you feel distress or discomfort as a result of taking part in the study, we can talk about whether it is best for you to withdraw. If you decide you no longer want to be involved, you can withdraw immediately and you do not need to explain your reasons for doing so.

## ***Part Two***

### ***What will happen if I don't want to carry on with the study?***

You may withdraw from the study at any time. If you do wish to withdraw then I will ask you whether you are happy for me to keep any recorded information relating to you, but if you are not happy with this all information that has been recorded about you will be permanently destroyed. Your decision to leave this study will not affect your employment rights in any way.

### ***What if there is a problem?***

If you have a concern about anything you are very welcome to speak to me, and I will do my best to answer your questions. You can contact me on the numbers and/or email address given at the end of the information sheet. If you remain unhappy and wish to complain formally you can do this through the University of Bath. As well as this, at any point, you can also speak with either of my supervisors, Dr. David Wainwright and Dr. Rachael Gooberman-Hill (their contact details can also be found at the end of the information sheet).

### ***Will my taking part in this study be kept confidential?***

All information that is collected during the study will be kept strictly confidential and all identifiable information will be removed so that no names or places can be identified. No information will be used or made available for any purposes other than for this study. Only my supervisors and I will have access to any information. With consent, information will be stored securely at the University of Bath. Everything you say/report is confidential unless you tell me something that indicated that you or someone else is at risk of harm. I would discuss this with you before telling anyone else.

### ***What will happen to the study's results?***

Upon completion of the study, a thesis will be submitted as part of my PhD. Some of the information I collect may be kept and stored in a repository after the study is completed. The results may also be used for presentations at conferences and for publications. I will also ask for your consent to include direct quotes from the study in these. All names and places will be kept anonymous, which means that nobody will be able to identify who you are and where you work. I will also take care to disguise other potentially identifying characteristics, such as ethnicity/country of origin.

### *Who is organising and funding the study?*

The study is organised by myself, Carys Banks, and is part of my PhD project that I am undertaking at the University of Bath, and which is funded by The Economic Social Research Council (ESRC).

### *Who has reviewed the study?*

Before this study goes ahead, it must be checked by an Ethics Committee, both at the University of Bath and an external Social Care Ethics Committee, who make sure that what I want to do is fair and safe. Approval for this study was given by these committees on 25/06/14 and 03/07/14. Before starting this study, I have also taken part in all the necessary Disclosure and Barring Services checks (DBS).

### *Any questions or problems:*

If you require any further information before deciding, or have any queries about anything concerning the study, please feel free to contact me:

Carys Banks (PhD student)

01225 385 833



c.a.banks@bath.ac.uk

Or, you can also speak to my supervisors:

Dr. David Wainwright (project supervisor)

Senior Lecturer-School for Health

University of Bath

Email: d.wainwright@bath.ac.uk

Dr. Rachael Gooberman-Hill (project supervisor)

Senior Research Fellow-School of Clinical Sciences

University of Bristol

Email: R.Gooberman-Hill@bristol.ac.uk

**Thank you for considering taking part in my research and taking time to read this information sheet.**



### CONSENT FORM FOR SUPPORT WORKERS/OTHER STAFF

#### Understanding care and support for people with learning disabilities

Thank you for considering taking part in this research. If you have any questions please ask me before you decide whether to take part. You will be given a copy of this consent form to keep and refer to at any time.

- |  |     |    |
|--|-----|----|
| 1. I confirm that I have read and understand the information sheet dated 18.06.14 (Version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | YES | NO |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my employment or legal rights being affected.   | YES | NO |
| 3. I understand that researchers involved in this study from the University of Bath and University of Bristol may look at data collected during the study.   | YES | NO |
| 4. I understand that anonymised data collected during this study may be kept and securely stored after the study is completed.   | YES | NO |
| 5. I understand that if I withdraw from the study I can request for the data collected up to that point to be destroyed, but I must do this before the whole study is completed.   | YES | NO |
| 6. I understand that if I take part in an interview, I will be asked if it can be recorded with an audio voice recorder. But, I also have the option of taking part in an interview without it being recorded.                       | YES | NO |
| 7. I understand that data collected about me during the study may be used in publications, which will be made anonymous.   | YES | NO |
| 8. I agree to take part in the above study.  | YES | NO |

Name of participant:

Signature:

Date

Name of researcher:

Signature:

Date

When completed: one copy for participant, one copy for researcher site.

## **APPENDIX 4**

- **Social Care Research Ethics Committee NRES approval correspondence.**
- **University of Bath Research Ethics Approval Committee for Health (REACH) approval correspondence.**
- **Disclosure & Barring Service (DBS) Enhanced Certificate.**

## APPENDIX 4

### Social Care Research Ethics Committee NRES approval correspondence.



#### **Social Care REC**

*An NRES Research Ethics Committee*

25 June 2014

Miss Carys Anna Banks  
Doctoral Student  
Department for Health  
University of Bath  
1 West, 4.111  
Claverton Down  
Bath  
BA2 7AY

Dear Miss Banks

<b>Study title:</b>	<b>The vulnerable empowered? An exploration of political reform in social care for adults with intellectual disability</b>
<b>REC reference:</b>	<b>14/IEC08/0019</b>
<b>Protocol number:</b>	<b>N/A</b>
<b>IRAS project ID:</b>	<b>151542</b>

Thank you for your letter of 18 June 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 17 June 2014

#### **Documents received**

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper		18 June 2014
Other [Letter for family and/or supportive others]	3	18 June 2014
Participant consent form [Support Workers]	3	18 June 2014
Participant consent form [Adults with Learning Disabilities]	3	18 June 2014
Participant information sheet (PIS) [Support Workers]	3	18 June 2014

#### **Approved documents**

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper		19 June 2014
Covering letter on headed paper		30 May 2014

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## APPENDIX 4

14/IEC08/0019

Page 2 of 2

Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		15 July 2013
Letter from sponsor		16 April 2014
Other [Dr Rachel Goberman-Hill - Supervisor CV]		14 April 2014
Other [Letter for family and/or supportive others]	3	18 June 2014
Other [Dr David Wainwright - Supervisor CV]		14 April 2014
Participant consent form [Support Workers]	3	18 June 2014
Participant consent form [Adults with Learning Disabilities]	3	18 June 2014
Participant information sheet (PIS) [Adults with Learning Disabilities]	2	23 May 2014
Participant information sheet (PIS) [Support Workers]	3	18 June 2014
REC Application Form	151542/5967 12/27/662	14 April 2014
Research protocol or project proposal	1	14 April 2014
Summary CV for Chief Investigator (CI)	Miss Carys Anna Banks	10 April 2014

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

**14/IEC08/0019**

***Please quote this number on all correspondence***

NRES/HRA are pleased to welcome researchers and R & D staff at their NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

Yours sincerely



**Barbara Cuddon**  
**Social Care Research Ethics Committee Co-ordinator**  
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Social Care REC Website: [www.sciec.org.uk](http://www.sciec.org.uk)


Copy to: *Professor Jane Millar, Department for Health, University of Bath, 4 West 3.22 Claverton Down, Bath, BA2 7AY*



University of Bath Research Ethics Approval Committee for Health (REACH) approval correspondence.

## APPENDIX 4

### Disclosure & Barring Service (DBS) Enhanced Certificate.

<b>Enhanced Certificate</b> Page 1 of 2		 Disclosure & Barring Service
<b>Certificate Number</b> 001439253543		
<b>Date of Issue:</b> 24 MARCH 2014		
<b>Applicant Personal Details</b>	<b>Employment Details</b>	
Surname: BANKS	Position applied for: ADULT WORKFORCE RESE ARCH STUDENT (COMMUNITY)	
Forename(s): CARYS ANNA	Name of Employer: UNIVERSITY OF BATH	
Other Names: NONE DECLARED		
Date of Birth: 27 SEPTEMBER 1982	<b>Countersignatory Details</b>	
Place of Birth: CROYDON	Registered Person/Body: THE UNIVERSITY OF BATH	
Gender: FEMALE	Countersignatory: JANE HENNESSY	
<b>Police Records of Convictions, Cautions, Reprimands and Warnings</b> NONE RECORDED		
<b>Information from the list held under Section 142 of the Education Act 2002</b> NOT REQUESTED		
<b>DBS Children's Barred List information</b> NOT REQUESTED		
<b>DBS Adults' Barred List information</b> NONE RECORDED		
<b>Other relevant information disclosed at the Chief Police Officer(s) discretion</b> NONE RECORDED		
<b>Enhanced Certificate</b> This document is an Enhanced Criminal Record Certificate within the meaning of sections 113B and 116 of the Police Act 1997.		
THIS CERTIFICATE IS NOT EVIDENCE OF IDENTITY		<b>Continued on page 2</b>
DBS Disclosure and Barring Service, PO Box 165, Liverpool, L69 3JD Helpline: 0870 90 90 811		© Crown Copyright



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Certificate Number 001439253543

**Use of certificate information**

The information contained in this certificate is confidential and all recipients must keep it secure and protect it from loss or unauthorised access. This Certificate must only be used in accordance with the Disclosure and Barring Service's (DBS) Code of Practice and any other guidance issued by the DBS. Particular attention must be given to the guidance in the fair use of the information in respect of those whose Certificate reveals a conviction or similar information. The DBS will monitor the compliance of Registered Bodies with this Code of Practice and other guidance.

This Certificate is issued in accordance with Part V of the Police Act 1997, which creates a number of offences. These offences include forgery or alteration of Certificates, obtaining Certificates under false pretences, and using a Certificate issued to another person as if it was one's own.

This Certificate is not evidence of the identity of the bearer, nor does it establish a person's entitlement to work in the UK.

**Certificate content**

The personal details contained in this Certificate are those supplied by or on behalf of the person to whom the Certificate relates at the time the application was made and that appear to match any conviction or other details linked to that identity.

The information contained in this Certificate is derived from police records, and from records held of those who are unsuitable to work with children and/or adults, where indicated. The police records are those held on the Police National Computer (PNC) that contains details of Convictions, Cautions, Reprimands and Warnings in England and Wales, and most of the relevant convictions in Scotland and Northern Ireland may also be included. The DBS reserves the right to add new data sources. For the most up to date list of data sources which are searched by the DBS please visit the DBS website.

The Other Relevant Information is disclosed at the discretion of the Chief Police Officers or those of an equivalent level in other policing agencies, who have been approached by the DBS, with due regard to the position sought by the person to whom the Certificate relates.

**Certificate accuracy**

The DBS is not responsible for the accuracy of police records.

If the person to whom this Certificate relates is aware of any inaccuracy in the information contained in the Certificate, he or she should contact the Countersignatory immediately, in order to prevent an inappropriate decision being made on their suitability. This Countersignatory will advise how to dispute that information, and if requested arrange for it to be referred to the DBS on their behalf. The information should be disputed within 3 months of the date of issue of the Certificate.

The DBS will seek to resolve the matter with the source of the record and the person to whom the Certificate relates. In some circumstances it may only be possible to resolve a dispute using fingerprints, for which consent of the person to whom the Certificate relates will be required.

If the DBS upholds the dispute a new Certificate will be issued free-of-charge. Details of the DBS's disputes and complaints procedure can be found on the DBS's website.

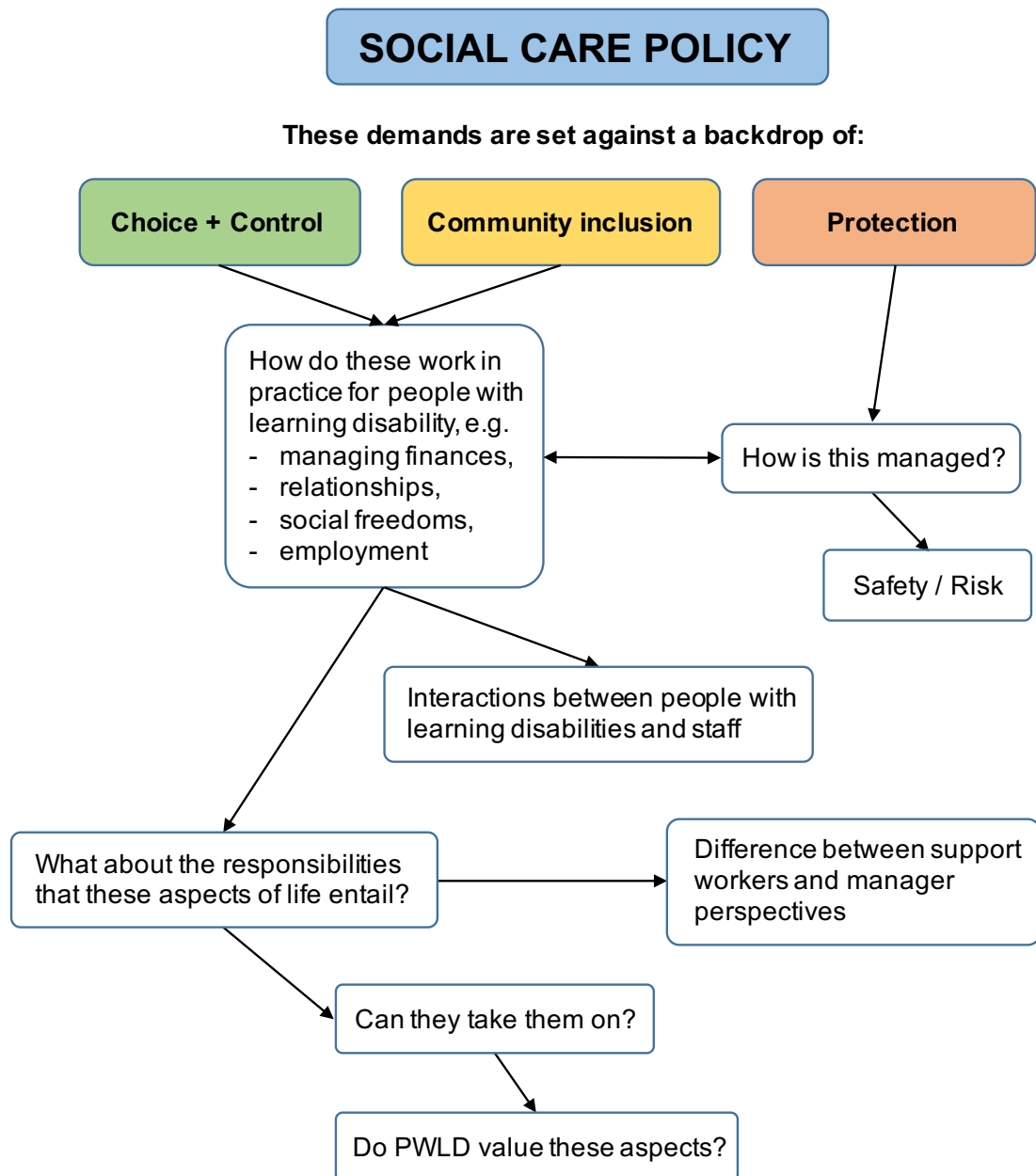
**Contact us**

Post:	Disclosure and Barring Service PO Box 165 Liverpool L69 3JD	Telephone:	Customer Services: 0870 90 90 811 Welsh line: 0870 90 90 223 Minicom: 0870 90 90 344 General Information 0870 90 90 811
Web:	<a href="http://www.gov.uk/dbs">www.gov.uk/dbs</a>		
Email:	<a href="mailto:customerservices@dbs.gsi.gov.uk">customerservices@dbs.gsi.gov.uk</a>		

If you find this certificate and are not able to return it to the person to whom it relates, please return it to the DBS at the address above or hand it in at the nearest police station.

**End of Details**

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**Examples of broad questions/areas of discussion:**

- Their role and background
- Perception of the developments in learning disability services, e.g. the growth in promoting choice and independence – what do they think of this?
- Do they view their area of services/or services overall as having problems, and if so, what are these?
- The tension between independence and protection – examples of these taking place in everyday practice, and can they be resolved?
- Responsibility as a central component of 'good' choice making – how does this work for people with cognitive impairments?

**Figure A.** Broad themes guiding interviews and conversations (mainly with staff) which provides a flavour of the overall ideas guiding these discussions. During interviews, questions and discussions were directed in more specific ways according to whom I was speaking and observing.

**Table A. Interviews.**

Interviewee name(s)	Organisation	Role within organisation		Interview		
				Date	Location	Duration <sup>s</sup> Mode of recording
Jo Parry	Hear Us	Owner/manager		29/07/2014	Hear Us head office	55 Handwritten notes
Hatti Staple	national learning disability organisation	Chief executive		30/07/2014	Telephone interview	45 Handwritten notes
Eric Williams and Helen Saunders	Cambrick	Clinical commissioning group		31/07/2014	Head office, Cambrick	48 Handwritten notes
Nigel Sutton (1 <sup>st</sup> interview)	Singertree Trust	Locality manager		08/09/2014	Local café	62 Audio recorded
Steve Connors	Station Park Café	manager, outreach/community development worker		02/10/2014	Station Park Café	79 Audio recorded
Sally French	Freelance advisor	Sanderstead View		10/09/2014	Local café	90 Audio recorded
James Walter	Singertree Trust	Head office, Viewpark Centre		26/20/2014	Sanderstead View	79 Audio recorded
Sally French and Janet Leyes		Freelance advisors		13/11/2014	Janet's home	73 Audio recorded
Michael Roberts	Singertree Trust	Job coach		20/01/2015	Head office, Viewpark Centre	95 Audi recorded
Phillip Brown	Cambrick	Linsfield day centre manager		02/02/2015	Linsfield day centre	45 n/a interview undertaken during a tour of the day service
April Whyatt		Mark Whyatt's mother		07/02/2015	Sanderstead View	103 Audio recorded
Anna Dun	Cambrick	Speech and language therapist		12/02/2015	Head office, Cambrick	49 Audio recorded
Graham Willis	Singertree Trust	Job coach		16/02/2015	Head office, Viewpark Centre	70 Handwritten notes (Graham requested not to be recorded)
Catherine Smith	Cambrick	Job coach at Employment Now		27/02/2015	Local sites of employment for people with learning disabilities and the Employment Now training classroom	90 n/a interview conducted during a tour of the services

**Table A.** (continued)

Interviewee name(s)	Organisation	Role within organisation	Interview		
			Date	Location	Duration <sup>§</sup> Mode of recording
Sarah Hill	Singertree Trust	Operations manager	20/03/2015	head office, Viewpark Centre	54 Audio recorded
Nigel Sutton (2 <sup>nd</sup> interview)	Singertree Trust	Locality manager	02/04/2015	head office, Viewpark Centre	52 Audio recorded
Fred Peck and Julie Davies	Cambrick	Locality manager and Hilltop day centre manager	07/04/2015	Hilltop Mews day centre	75 Audio recorded

<sup>§</sup> Duration of interviews rounded to the nearest minute.

## **APPENDIX 6**

### **Searching and selecting the literature and policy documents for review**

#### **Introduction**

This section provides details of the methods used to search and analyse the literature and policy documents that informed the direction of this research and research question. The aim here was to set out the boundaries of existing knowledge in this area, in terms of what has been said to date. Doing this, enabled me to determine the gaps in relation to developing my research question.

#### **Literature**

Given the crossover between policy, its implementation and the lived experiences of people with learning disabilities and their support staff, it was necessary to treat this as an interdisciplinary research project. This meant that I was required to read widely across a range of disciplinary fields, including anthropology, psychology, medical sociology, philosophy, political theory, social policy and health and social care. This breadth was reflected in the search engines and bibliographic information systems that I utilised. Key online systems included (in alphabetical order): Anthropology Plus, AnthroSource, Archive Hub, British Library of Economic and Political Science (BLPES), ESRC Society Today, Google Scholar, International Bibliography of the Social Sciences (IBSS), JSTOR, Oxford Bibliographies Online – Anthropology, Political Information, PsycINFO, SAGE Publications Ltd, Scopus and Web of Science.

Searches were organised around key words that, at the start of the research, I deemed to be relevant, and which would be useful in 'getting the ball rolling' in terms of knowledge development. As such, at the early stages of searching, the key words used were relatively inclusive, including: UK learning disability social care support, learning disability UK policy and legislation, people with learning disabilities and support workers. These words were combined with one or more of the following: choice, control, independence, autonomy, protection, risk, tensions between autonomy and protection, care relationships in social care, community inclusion.

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The up-to-date literature and journal article searches were balanced with landmark/classic texts, which have provided foundational ideas and theories in the areas of learning disability, policy, social care and care more generally. These texts were sourced predominantly from previous and current supervisors, colleagues, conferences and through library and internet searches. In relation to all the above, when reading the sourced literature, I also looked at their bibliographies and used these as leads to move on to further authors, ideas and theories. This allowed me to continuously keep up-to-date with and widen the relevant material.

### Policy documents

Given that a central aspect of the research question required a grasp of previous and current UK policy and legislation, it was necessary that I identified the central policy and legislative documents in this field. This was done through searching GOV.UK and Google Scholar. Importantly, as this research intended to be a critique of policy rhetoric, it was also necessary that I included literature that has critiqued these policy and legislation documents, such as academic literature, as well as literature/documents from the third sector and other independent organisations. Accordingly, these were searched through the search engines and bibliographic information systems outlined on p.274.

The publication of *Valuing People* in 2001 was the first government white paper on learning disability in 30 years, and so this document represented a significant moment in learning disability policy. Indeed, although the Care Act 2014 now provides the legal framework for all adult social care, *Valuing People* has remained a significant guiding policy document in UK practice. In order to draw out a sense of the contemporary context in which UK learning disability support is situated, the document analysis began with reading of *Valuing People*, 2001, as well as its follow up document from 2009, *Valuing People Now* (Department of Health, 2001; 2009a). From these documents, I identified key concepts around policy objectives which then informed analysis of further government documents. For instance, the focus within *Valuing People* on personalisation and personal budgets, as well as with employment in *Valuing People Now*, informed my



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decision to read the relevant documents relating to these areas. During this process, a wide range of documents was read, but only documents I identified as key documents – those which pertained specifically to empowerment and protection policies – were analysed in detail using thematic analysis (Boyatzis, 1998; Auerbach & Silverstein, 2003; Emerson, Fretz & Shaw, 2011). Details of the processes of thematic analysis are described in the section below.

### **Analysing literature and policy document sources**

Analysing literature and document sources was a key process in the research. The literature and documents yielded from the searches described above were collated into broadly grouped areas including:

- government policy;
- legislation and safeguarding;
- neo-liberal policies and disability social theories (including critiques of these);
- the third sector;
- critiques of individualism/agency;
- quality of life;
- relationship between empowerment and protection;
- relationship between policy and practice;
- ethics and care ethics;
- employment;
- in addition to these groupings, I also created sub-groups based on the research methodologies used in each study.

The literature and policy documents within these groups were analysed using thematic analysis (Boyatzis, 1998; Auerbach & Silverstein, 2003; Emerson, Fretz & Shaw, 2011), through which key themes and issues were drawn out. In guiding this process, I predominantly focused around how policy is experienced by people with learning disabilities and support staff in everyday practice, how this impacts upon and is impacted by wider factors, and how these relational dynamics might be best understood through a research context. This involved

## APPENDIX 6

studying texts and identifying and interpreting themes, in the form of patterns or dissonances that related to the above, as well other themes not relating to the above but deemed to be of interest and importance to the research aims. These processes then allowed me to begin to funnel the sourced materials into a more clearly defined path. The following table (see Table A), on p.278 provides some examples of the early overarching themes, issues and questions arising from the literature searches, which were taken into the literature review.

A significant part of the early document analysis involved exploring the development of learning disability policy, which included reading about how the institution as a model of care came into being. With this, I explored how this model developed over the 20<sup>th</sup> century, including how it was shaped by social, political and economic movements, which eventually led to its transformation into the Care in the Community model that most resembles the type of care and support that is provided in the UK today.

In accordance with the stance I have taken towards understanding lived experiences as accounts of subjective and multiple realities, I viewed the contents of these documents as one such subjective reality against a backdrop of social, political and economic movements. I used these documents as a way of building up a picture of how the various identities of people with learning disabilities have been constructed over time, including how these constructions were being equated to a particular kind of good life for people with learning disabilities.

## APPENDIX 6

**Table A.** Overarching themes, issues and questions arising from the literature and policy document searches that were taken into the literature review.

Policy	Methodology
<ul style="list-style-type: none"> <li>- The development of policy within UK based learning disability support</li> <li>- Institutionalisation</li> <li>- Care in the Community model</li> <li>- Person-centred support</li> <li>- The role of independent and third sector</li> </ul>	<ul style="list-style-type: none"> <li>- What empirical approaches have been used to explore the lived experiences of this policy implementation?</li> <li>- What were the main objectives of these approaches?</li> <li>- The complexity of the structures influencing policy development indicates that the lived experience of policy needs to be understood through in-depth research and over the long term</li> </ul>
<b>Social and political movements</b> <ul style="list-style-type: none"> <li>- Social democracy</li> <li>- Disability theories</li> <li>- Neo-liberal economics</li> <li>- Third Way politics</li> </ul>	